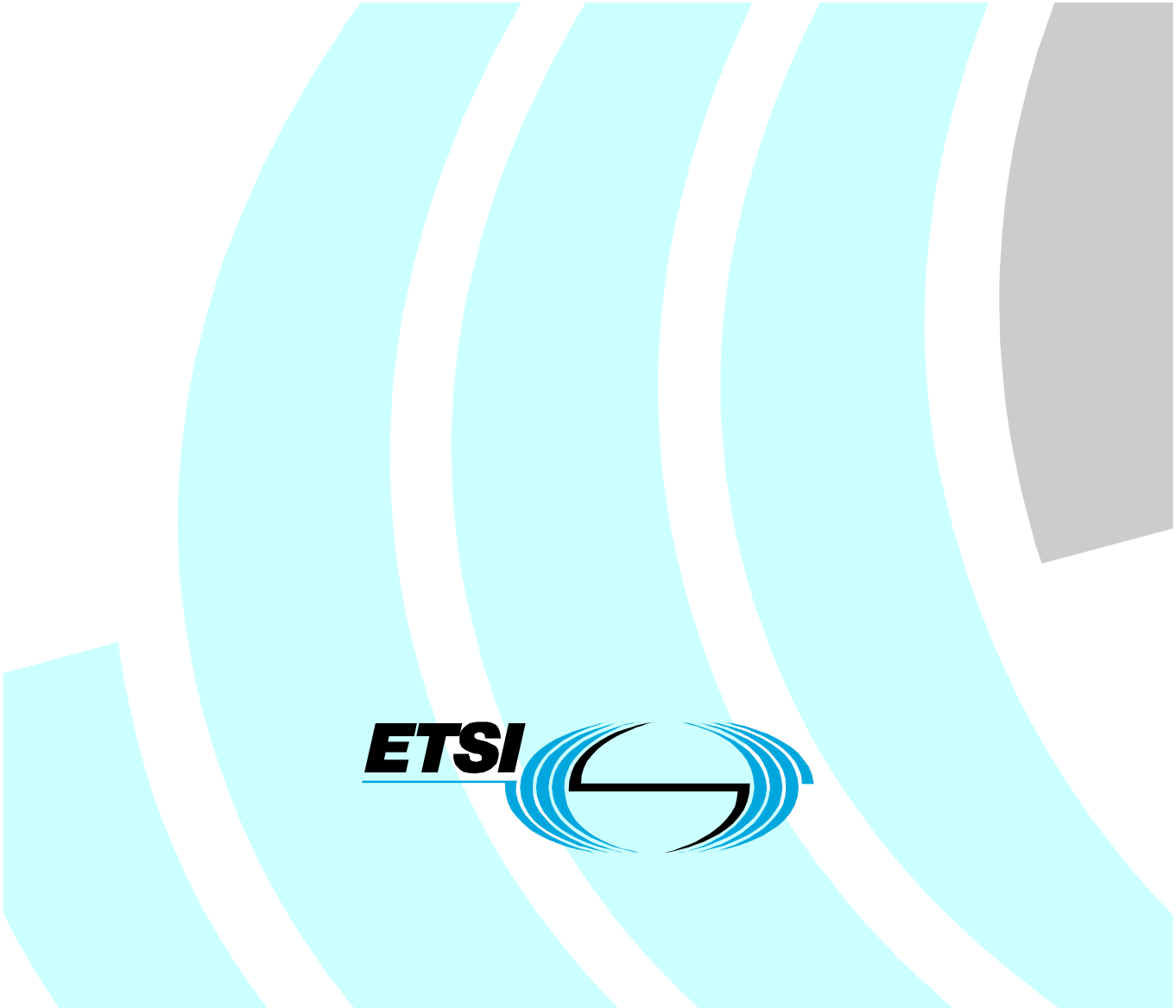
# ETSI TR 102 415 V1.1.1 (2005-08)

*Technical Report*

# Human Factors (HF);
# Telecare services;
# Issues and recommendations for user aspects



Reference
DTR/HF-00049

Keywords
Design for All, health, HF, intelligent homes & buildings, interface, MMI

***ETSI***

650 Route des Lucioles
F-06921 Sophia Antipolis Cedex - FRANCE

Tel.: +33 4 92 94 42 00 Fax: +33 4 93 65 47 16

Siret N° 348 623 562 00017 - NAF 742 C
Association à but non lucratif enregistrée à la
Sous-Préfecture de Grasse (06) N° 7803/88

# Contents

Intellectual Property Rights ..... 5
Foreword ..... 5
Introduction ..... 5
1 Scope ..... 8
2 References ..... 8
3 Definitions and abbreviations ..... 15
3.1 Definitions ..... 15
3.2 Abbreviations ..... 16
4 Telecare and its service provisioning elements ..... 17
4.1 Definitions and approach ..... 17
4.2 Electronic assistive technology services ..... 19
4.2.1 General ..... 19
4.2.2 Examples and scenarios ..... 20
4.2.3 Providing integrated models ..... 22
4.2.4 Searchable databases ..... 22
4.2.5 Virtual stores ..... 23
4.2.6 Future development ..... 23
4.3 Home safety and security monitoring services ..... 23
4.3.1 General ..... 23
4.3.2 Examples and scenarios ..... 23
4.3.3 Precautions, reliability and fail-safe operation ..... 24
4.3.4 Equipment integration, interoperability and user confidence ..... 24
4.3.5 Examples of commercial surveillance services ..... 25
4.3.6 Future development ..... 25
4.4 Information, communication and educational services ..... 25
4.4.1 General ..... 25
4.4.2 Examples and scenarios ..... 27
4.4.3 Future development ..... 28
4.5 Personal monitoring services ..... 28
4.5.1 General ..... 28
4.5.2 Examples and scenarios ..... 29
4.5.3 Overview of technologies and standards ..... 31
4.5.4 Future development ..... 32
4.6 User-centred integration of telecare service elements ..... 33
5 Deployment drivers, enablers and obstacles ..... 33
5.1 Demographics, policy frameworks and the economic feasibility of telecare services ..... 33
5.2 Clients, carers and coordinators ..... 35
5.2.1 Clients as drivers of telecare services ..... 35
5.2.1.1 A positive attitude towards ICT ..... 35
5.2.1.2 Population mobility and family infrastructure ..... 35
5.2.1.3 Efficient usage of resources ..... 36
5.2.1.4 Healthcare services to people in remote regions ..... 36
5.2.2 Carers as drivers of telecare services ..... 36
5.2.2.1 Care centres ..... 36
5.2.2.2 Professional carers ..... 36
5.2.2.3 Informal carers ..... 37
5.3 Telecommunication technologies and services ..... 37
5.4 Equipment, device and solution providers ..... 38
5.5 Obstacles ..... 39
5.5.1 Fear and negative attitudes towards technology ..... 39
5.5.2 Cultural and religious aspects ..... 39
5.5.3 Freedom and independence ..... 39

6 Stakeholders' requirements and goals....40
6.1 General....40
6.2 Clients....40
6.2.1 Babies....40
6.2.2 Children....41
6.2.3 Older, impaired and disabled users....42
6.2.3.1 Physical impairments....43
6.2.3.2 Sensory impairments....43
6.2.3.3 Cognitive impairments....44
6.2.3.4 Other impairments....45
6.2.3.5 Effects of aging....45
6.2.4 Clients with chronic needs....45
6.2.5 Other clients....46
6.3 Carers....46
6.3.1 Professional carers....46
6.3.2 Informal carers....47
6.4 Coordination agents....47
6.5 Healthcare providers....48
6.6 Social care providers....49
6.7 Third party suppliers and the voluntary sector....49
6.8 Housing and infrastructure providers....49
6.9 Access and telecommunication providers....50
6.10 Equipment vendors....51
6.10.1 Electronic assistive technologies (EAT)....51
6.10.2 Home safety and security monitoring....52
6.10.3 Information provisioning....52
6.10.4 Personal monitoring systems....52
6.11 Conflicting goals....53

7 Human factors and the usability of telecare services....53
7.1 Usability, accessibility and UI issues....53
7.2 Setup, configuration and initial use....54
7.3 User education....55
7.4 Ubiquity of access, interoperability, customization and personalization....56
7.5 Other human factors aspects....56

8 Specific recommendations....58
8.1 Recommendations for telecare service provisioning elements....58
8.1.1 Electronic assistive technologies....58
8.1.2 Home safety and security monitoring....58
8.1.3 Information provisioning....58
8.1.4 Personal monitoring....59
8.1.5 Electronic health records....59
8.1.6 Interoperability and integrability....60
8.2 Recommendations to stakeholders....60
8.2.1 Policy makers and regulators....60
8.2.2 Standards developers....61
8.2.3 Infrastructure providers....62
8.2.4 Service providers....62
8.2.5 Device, equipment and application developers....62
8.2.6 User experience and UI professionals....63
8.3 Recommendations for ethical, privacy and security aspects of telecare services....63
8.3.1 Ethics and non-intrusiveness....63
8.3.2 Privacy and security of personal data....63

9 Conclusions, general recommendations and future work....66

History....68

# Intellectual Property Rights

IPRs essential or potentially essential to the present document may have been declared to ETSI. The information pertaining to these essential IPRs, if any, is publicly available for **ETSI members and non-members**, and can be found in ETSI SR 000 314: *"Intellectual Property Rights (IPRs); Essential, or potentially Essential, IPRs notified to ETSI in respect of ETSI standards"*, which is available from the ETSI Secretariat. Latest updates are available on the ETSI Web server (http://webapp.etsi.org/IPR/home.asp).

Pursuant to the ETSI IPR Policy, no investigation, including IPR searches, has been carried out by ETSI. No guarantee can be given as to the existence of other IPRs not referenced in ETSI SR 000 314 (or the updates on the ETSI Web server) which are, or may be, or may become, essential to the present document.

# Foreword

This Technical Report (TR) has been produced by ETSI Technical Committee Human Factors (HF).

Intended users of this ETSI Technical Report (TR) are those planning, deploying and implementing telecare services: standards developers (ETSI & others), service providers, legislators, policy makers, regulators and implementers, solution and equipment providers, interaction designers, developers of fixed and mobile terminal devices, services and applications and developers of telecare services.

# Introduction

Telecare services include health-and social care related information provided through the telephone or the Web, automated appointment reminders, client monitoring services at home or on the move, the identification of emergency situations, et cetera.

In a historical perspective, medical treatment, cure and care until the mid-1900s used to be provided by trained (or at least, experienced) physicians in the client's home, family and neighbours acting as nursing and supportive staff.

During the development of modern life of the 20th century, this healthcare model has changed dramatically. Medical care is nowadays most often care unit-centric, often requiring access to advanced medical equipment. A General Practitioner or specialist Medical Doctor's visit to the client's home has become an unusual service.

As a measure to overcome distances, telemedicine was introduced in the 1960s as isolated, stand alone efforts [104]. The first community alarm services were introduced at the University of Nebraska College of Medicine in 1959 [99]. This was soon to be followed by telephone- or videoconference-based televisit services, as documented in [100].

Social care services have been supported and extended by Information and Communication Technologies (ICT) during the last 10 to 15 years (through e.g. call centre based services, home equipment for social alarms, etc.). The underlying technology, as well as the availability of these services, did not change much during the last decades.

The more widespread deployment of telecare services was held back by several factors, including the:

- lack of efficient and reliable telecommunication networks and devices with the necessary capabilities;
- unavailability of hardware and software at reasonable costs;
- lack of on-line connectivity;
- relatively stable demographics;
- lack of political conviction, initiatives and support;
- lack of client trust, acceptability and client expectations and habits;
- resistance from healthcare professionals (social patterns take generations to change);
- lack of proven outcome benefits.

Users were not ready yet, nor were the prerequisites- technology, society, technical infrastructure, practitioners, procedures, budgets, et cetera- available and established for a successful deployment.

The proliferation of fixed and mobile broadband services in and outside the home is opening up opportunities for the delivery of telecare services. Thereby, the demand for end user (client) centric human factors guidelines addressing design, development, deployment, use and maintenance of telecare services is on the increase.

In the 1990s, digital technology enablers (infrastructures, terminals and services) became available to the mass market. At present, demographic changes, limited resources, high user expectations, globalization and technology are transforming medical and social care systems in many countries. The penetration of ever-smarter devices connecting to mobile communication networks and the World Wide Web through fixed and mobile Internet, combined with society-oriented, Europe-wide initiatives, health and social care service providers' support, evidence of the existence of demographic and economical feasibility enablers, accepted changes in the delivery of health and social care services and the progress achieved in the area of medical technologies, pharmaceuticals and disposable products enable the deployment of telecare services.

According to the United Nations Developing Programme, better health care services are required on a global level, but its costs and expenses are not allowed to continuously increase (without a collapse of the system in the aging Western world). It is estimated that in 2051, 40 % of the European population will be 65 yeas or older.

Responding to demands for better healthcare raised by an aging population can increase the cost pressure at a time when health care spending is already on the increase. In 1970, the healthcare-related spending of the Organisation for Economic Co-operation and Development (OECD - www.oecd.org) countries averaged 5 % of GDP. This increased to 7 % in 1990 and is more than 8 % at present. In addition, it exceeds 10 % in Germany, Sweden, Switzerland and the United States.

More than 75 % of all OECD health spending is publicly financed. Based on assessment of countries' experiences, analysis of underlying issues and review of evidence and in order to control the increasing pressure, OECD recommends actions including the introduction of automated health-data systems, strategies making use of new technologies and improved quality of care through better information.

The European Commission encourages EU Member States to seek a balanced status among the detected needs of providing quality care and social services to citizens, being compliant to standards, containing costs at a national level, and managing services at a local level. "*e*-Health is today's tool for substantial productivity gains, while providing tomorrow's instrument for a restructured, citizen-centred health system and, at the same time, respecting the diversity of Europe's multi-cultural, multi-lingual health care traditions" [29]. A key ambition is better care services at the same or a lower cost.

In addition, telecare has been identified and pointed out by several national European Governments (e.g. in the UK, by the Community Care Minister, Stephen Ladyman) as a strategic enabler of the provision of independent living to older people in their own homes, driven by demographics and new equipment technologies. The market is poised to expand rapidly over the coming years.

The *e-Europe* 2005 action plan is built around two main groups of actions: stimulate services, applications and content - both online public services and e-business - and the underlying (fixed and mobile) broadband infrastructure, including security matters. *e-Europe* has recognized that "…the information society has much untapped potential to improve productivity and the quality of life" and that this potential "…is growing due to the technological developments of broadband and multi-platform access". It provides a policy framework to stimulate the development of ICT infrastructure and application within Europe to enable the citizens to benefit from the growth of the information society. *e*-Health has been identified as one of the priority objectives of the *e-Europe* 2005 Action Plan [29] and the *e*-Health Action Plan identified and set up the practical steps required to build a "European *e*-Health area":

- Basic level: by mid-2004, a European Health Identity Card (EHIC) shall be introduced (already achieved).
- National level: by 2005, EU member states are required to develop national and regional *e*-Health strategies.
- Interoperability level: by 2006, national healthcare networks should be well advanced in their efforts to exchange information, including client identifiers.
- Networked level: by 2008, health information and services such as *e*-prescription, *e*-referral, telemonitoring and telecare, are to become commonplace, accessible over both fixed and mobile broadband networks.

The above means that by 2008, telecare services should be provided and be accessible over both fixed and mobile broadband networks in the European Union.

From the social care perspective, the 2005-2006 Work Programme of the EU's applied IST research defines the following key strategic eInclusion objectives [106]:

- to mainstream accessibility in consumer goods and services, including public services through applied research and development of advance technologies. This will help ensure equal access, independent living and participation for all in the Information Society; and
- to develop next generation assistive systems that empower persons with (in particular cognitive) disabilities and aging citizens to play a full role in society, to increase their autonomy and to realize their potential.

By means of user experience, telecare services could gain considerable benefits from applying human factors expertise, developed in various areas of ICT, during the past decades.

The present document is intended to be a first prestudy of the area, before human factors guidelines for telecare services can be developed. The present document provides support for the *e*-Europe policy framework to move forward on the delivery of on-line public services in the health and social care sectors, by enabling and improving the delivery of telecare services with a good user experience.

Human factors and the user experience of telecare solutions is a complex area, given the large number of influencing elements involving the establishment of human confidence, device setup, configuration, calibration and maintenance, data collection, user procedures, cultural issues such as the use of language and illustrations, the organization of the care provisioning process, and communication with diagnostic systems and carers, human communication and confirmation and decision making, the presentation medium and accessibility issues. In addition, as telecare services can be used not only in but also outside of homes, usability aspects relating to the specifics of mobile environments and equipment and service use need to be covered. Finally yet importantly, these services must be used by young, older people, impaired, disabled (see [25] and [11]) or temporarily ill people and should therefore be designed, deployed and maintained thereafter.

# 1 Scope

The present document addresses the end user aspects of telecare, with emphasis on the delivery of health and social care services, in and outside of connected (intelligent) homes, with the purpose of ensuring that human factors aspects are duly considered in the current rapid progress towards ICT-based delivery of health care services.

The present document identifies key stakeholders including end users (comprising clients, the person in need of care and health professionals, informal carers and care coordinators), their objectives and requirements, with the following perspectives:

- the enhancement of human interaction by ICT;
- proliferation of personal data and privacy concerns; and
- safety and security of equipment use, mis-use, non-use and malfunctioning.

Furthermore, the present document identifies and examines technical, organizational and cost-related barriers to the widespread deployment, adoption and use of telecare services, and recommends strategies to overcome these barriers.

The present document takes into account requirements of the widest possible generic client population, including the needs of older people, babies, children and disabled clients.

The present document provides generic guidance and specific recommendations to standards developers, operators, service providers, equipment suppliers, policy makers, designers and users of telecare services, applicable to:

- telecare service provision elements;
- stakeholders' concerns; and
- ethical, privacy and security aspects.

The present document should be considered as a human factors and user experience standardization study, "setting the scene". In addition, the present document provides recommendations for future work, including the development of human factors guidelines, recommended to be initiated as soon as possible.

# 2 References

For the purposes of this Technical Report (TR), the following references apply:

[1] ETSI TR 102 068: "Human Factors (HF); Requirements for assistive technology devices in ICT".

[2] ETSI ES 202 076: "Human Factors (HF); User Interfaces; Generic spoken command vocabulary for ICT devices and services".

[3] World Health Organization (WHO)- "eHealth Standardization Coordination Group: eHSCG standards list".

NOTE: Available at http://www.who.int/ehscg/resources/en/ehscg_standards_list.pdf

[4] The McKinsey Quarterly (May 2005): "The economic impact of an aging Europe (Farrell, D.)".

NOTE: Available at http://www.mckinseyquarterly.com/article_page.aspx?ar=1613&L2=7&L3=10

[5] ETSI EG 202 116: "Human Factors (HF); Guidelines for ICT products and services; "Design for All".

[6] ETSI TR 102 133: "Human Factors (HF); Access to ICT by young children; Issues and guidelines".

[7] ETSI EG 202 325: "Human Factors (HF); User Profile Management".

[8] ETSI TR 101 806: "Human Factors (HF); Guidelines for telecommunication relay services for text telephones".

[9] ETSI EG 202 191: "Human Factors (HF); Multimodal interaction, communication and navigation guidelines".

[10] ML Williams and AC Smith: "Paediatric outreach services - Journal of Paediatrics and Child Health - Volume 40, Numbers 9-10, September 2004, pp. 501-503(3)".

[11] European Commission, Directorate General Information Society: "Report from the Inclusive Communications (INCOM) subgroup, Working Document (January 2004)".

[12] W3C Working Draft (November, 2004): "Web Content Accessibility Guidelines (WCAG) version 2".

NOTE: Available at http://www.w3.org/TR/WCAG20/

[13] "The Platform for Privacy Preferences 1.1 (P3P1.1) Specification".

NOTE: Available at http://www.w3.org/TR/P3P11/

[14] World Population Prospects: "The 2002 Revision, Population database, United Nations Population Division".

[15] Gill, J. (2001): "Requirements for the Interconnection of Assistive Technology Devices and Information and Communication Technology Systems".

NOTE: Available at http://www.tiresias.org

[16] Nyseth, A. et al.:"The future Home" (in Norwegian). Telenor report R 24, 82 pages.

NOTE 1: ISBN 82-423-0597-8. Oslo, 2004.

NOTE 2: Available at http://www.telenor.com/rd/pub/rep04/R_24_2004.pdf

[17] Hestnes, B., Brooks, P. and Heiestad, S.: "Mobile Eye-phone - a study of relevance, effectiveness and user-perceived suitability". Telenor Report R 2/04.

NOTE: Available at http://www.telenor.com/rd/pub/rep04/R_2_2004.pdf

[18] Council Directive 93/42/EEC of 14 June 1993 concerning medical devices. Medical Devices Directive (MDD).

NOTE: Available at http://europa.eu.int/comm/enterprise/newapproach/standardization/harmstds/reflist/meddevic.html

[19] Löhr, H., Rosenvinge, J. H., Gammon, D., & Johnsen, J-A. K.: "Can Internet be helpful for individuals with serious mental disorders? User experiences from a clinical perspective" (in Norwegian). Journal of the Norwegian Psychological Association 2002; 39: 514-9.

[20] Norum, J., Grev A., Moen M.A., Balteskard L., Holthe, K.: "Information and communication technology (ICT) in oncology. Patients' and relatives' experiences and suggestions." Support Care Cancer. 2003; 11(5):286-93.

[21] Alzheimer's association: "Safety checklist for the home".

NOTE: Available at http://www.alzheimers.org.au/upload/cfswd11.qxp.pdf

[22] Wearable positioning devices.

NOTE: Available at http://www.istsec.fi/eng/Etuotteet.htm

[23] Home supervision brokers.

NOTE: Available at http://www.agingtech.org/about.aspx

[24] Smart Thinking: Dependability and Assistive Technology.

NOTE: Available at http://www.gdewsbury.ukideas.com/Dependability%20and%20AT.html

[25] CEN/CENELEC Guide 6: "Guidelines for standards developers to address the needs of older persons and persons with disabilities".

NOTE: This is the same document as ISO Guide 71, republished by CEN/CENELEC.

[26] International Classification of Diseases (ICD-10). (R) World Health Organization.

NOTE: Available at http://www.who.int/classifications/icd/en/

[27] ETSI EG 202 132: "Human Factors (HF); User Interfaces; Guidelines for generic user interface elements for mobile terminals and services".

[28] ISO/IEC 9241-11: "Ergonomic requirements for office work with visual display terminals (VDTs) - Part 11: Guidelines on usability".

[29] Commission of the European Communities: "e-Health- making healthcare better for European citizens: An action plan for a European e-Health area".

NOTE: Available at http://europa.eu.int/information_society/qualif/health/index_en.htm

[30] "Libro Blanco sobre la Atención a las Personas en Situación de Dependencia en España" Ministerio de Trabajo y Asuntos Sociales, Madrid, 2005.

[31] Barlow, J., Bayer, S. and Curry, R.: "New Care Delivery Models and the Deployment of Telecare: The Hospital of the Future". In Proceedings of the 3rd International Conference on the Management of Healthcare & Medical Technology, Warwick Business School, September 2003.

[32] Baxter, G.D., Monk, A.F., Doughty, K., Blythe, M. and Dewsbury, G: "Standards and the Dependability of Electronic Assistive Technology", in "Designing a More Inclusive World", Cambridge Workshop on UA and AT, edited by Keates, Clarkson, Langdon and Robinson, 2004.

[33] Robinson, T.N., Patrick, K., Eng, T.R., Gustafson, D: Science Panel on Interactive Communication and Health: "An evidence-based approach to interactive health communication: A challenge to medicine in the Information Age". JAMA 1998; 280(14):1264-9.

[34] ICTSB Project Team. "Design for All. Final report - May 2000".

NOTE: Available at http://www.ictsb.org/Activities/Documents/ICTSB%20Main%20Report%20.pdf

[35] Department of Health, UK. "Guide to Integrating Community Equipment Services", 2002.

[36] Nordic Cooperation on Disability (NSH) May 2004: "Provision of Assistive Technology in the Nordic Countries".

NOTE: ISBN 91-86954-69-5.

[37] The Disabled Living Centres Council: "Equipped for Action".

NOTE: Available at http://www.dlcc.org.uk/equippedforaction.htm

[38] Libro Blanco de la I+D+I sobre tecnologías al servicio de las personas con discapacidad y las personas mayores en España. CEAPAT-IMSERSO, Madrid, 2003.

NOTE: http://www.infodisclm.com/documentos/accesibilidad/lblanco_disc_mayores.pdf

[39] ETSI TR 102 279: "Human Factors (HF); Two surveys on assistive technology".

[40] Bureau of Industry and Security. U.S, Department of Commerce: "Technology Assessment of the U.S. Assistive Technology Industry - February, 2003".

[41] The Alliance for Technology Access "Resource Center Standards of Excellence".

NOTE: Available at http://www.ataccess.org/joinata/joinatacenterstandards.html

[42] González, F.: "Words about the construction of the new Europe". CADENA SER. June 16th, 2004.

NOTE: See http://www.cadenaser.com.

[43] ISO/IEEE 11073: 2004: "Health informatics - Point-of-care medical device communication".

NOTE: See parts 00000 :200x): "framework and overview", 10101 (2004): "Nomenclature" and 102 01 (2004): Domain Information Model.

[44] The Independent Living Institute.

NOTE: Available at www.independentliving.org

[45] STAKES: "Design for All".

NOTE: Available at www.stakes.fi/include/pam1.html

[46] Torjman, S: "Proposal for a National Personal Supports Fund". Caledon Institute of Social Policy - October 2000".

NOTE: ISBN 1-894598-27-X.

[47] STAKES: "Smart homes and social services".

NOTE: Available at http://www.stakes.fi/cost219/~smart2.htm

[48] The Lewin Group, Inc.:"Assessment of Approaches to Evaluating Telemedicine. Final Report".

NOTE 1: Prepared for the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. December, 2000.

NOTE 2: Available at http://aspe.hhs.gov/health/reports/AAET/aaet.htm#Ra4

[49] Dewsbury, G., Karen C., et al.: "Home Technology Systems" Housing Care and Support Journal, November 2002, Vol. 5 No. 4.

[50] Intelligent Clothing homepage.

NOTE: Available at http://www.intelligentclothing.com/about.html and http://www.intelligentclothing.com/wireless.html

[51] Marshall, M.: "Dementia and Technology: Some Ethical Considerations in Elderly people in Industrialized Societies".

NOTE: Edited by Heidrun Mollenkopf, Berlin: Ed. Sigma, 1996 ISBN 3-89404-154-4.

[52] ISO 9999: "Technical aids for persons with disabilities - Classification and terminology".

[53] Fisk, M.J.: "Telecare equipment in the home: Issues of intrusiveness and control". Journal of Telemedicine and Telecare 3 (Supplement 1): 30-2. 1997.

[54] Porteus, J., and Brownsell, S.: "Using telecare. Exploring technologies for independent living of older people". Anchor Trust, 2000.

[55] Nicolle C., Abascal, J. (ed.): Inclusive design guidelines for human computer interaction. Taylor & Francis, London, 2001.

[56] Moore P.R, Pu J., Wong C.B., Chong S.K. "Review of Delivery of Health Care using Pervasive Computing Technologies in the Home (MEDI-AID)". De Montfort University Mechatronics Research Group, 2004.

NOTE: Available at http://www.nextwave.org.uk/downloads/mediaid_jan04.pdf

[57] European smart house projects.

NOTE: Available at http://www.smart-homes.org

[58] The European Health Insurance Card EHIC.

NOTE: Available at http://www.ehic.ie/

[59] Systematized Nomenclature of Medicine - Clinical Terms (SNOMED-CT). (R) College of American Pathologists.

NOTE: Available at http://www.snomed.com/index.html

[60] CEN/ICSS e-Health Standardization Focus Group: Current and future standardization issues in the e-Health domain: Achieving interoperability. CEN, 2005.

NOTE: Available at http://www.centc251.org/ehealthfocusgroup.htm

[61] ETSI ETR 095: "Human Factors (HF); Guide for usability evaluations of telecommunications systems and services".

[62] Langheinrich, M.; "A privacy awareness system for ubiquitous computing environments". Ubicomp, 2002.

[63] Eurostat: Internet usage by individuals and enterprises 2004. ISSN 1561-4840, catalogue number: KS-NP-05-018-EN-N, 2005.

NOTE : Available at http://europa.eu.int/information_society/newsroom/cf/newsletterarchivedetail.cfm?day=13&month=5&year=2005&type=daily

[64] Jakobsen, M. H., Jensen, M., Thrane, K.: "Communication and coordination in dispersed families". Telenor R&D Report R 43/2003. Oslo, 2003.

NOTE: Available at http://www.telenor.com/rd/pub/publications/pub03/index.shtml

[65] Bergmo, T.S.: "The Economics of Teledermatology in Northern Norway". In Teledermatology, Wootton R. and Oakley A. (ed.). London, Royal Society of Medicine Press, 2002.

[66] Bergmo T.S., Dahl, L.B. and Hasvold, T: "Is transmission of heart murmurs via e-mail cost saving?" (in Norwegian). Tidsskrift for den Norske Lægeforening 2004; 124(6):785-7.

[67] Rinde, E., Nordrum, I. and Nymo, B.J.: "Telemedicine in rural Norway". World Health Forum 1993; 14(1):71-7. .

[68] ICESDOH: "Integrating Community Equipment Services. Topic Sheet: Telecare".

NOTE: Available at http://www.icesdoh.org/article.asp?printer=1&Topic=49.

[69] Disabled Living Centres Council. "Equipped for Action Model".

NOTE: Available at http://www.dlcc.org.uk/equippedforaction.htm

[70] National Council on Independent Living (NCIL): "Historical Perspective on HCBS".

[71] Moulton, G., Huyler, L., Hertz, J. and Levenson, M.: "Accessible Technology in Today's Business", Microsoft Press, 2002.

[72] van Berlo, A. et al.: "Design Guidelines on Smart Homes", COST 219bis.

NOTE: Available at http://www.stakes.fi/cost219/Smart%20Home%20Guidelines.doc

[73] Westin, A.: "Privacy and Freedoom", Atheneum, New York, 1967.

[74] OECD: "Recommendation concerning guidelines governing the protection of privacy and transborder flow of personal data", September 1980.

[75] Eschet, G.: "Adapting Fair Information Practices to Radio Identification Technology", University of California of Berkeley.

[76] Noble, S.M., Coast, J., Bengerw, J.A.: "A cost-consequences analysis of minor injuries telemedicine". Journal of Telemedicine and Telecare, 11(1), 15 - 19, 2005.

[77] "The expert patient: a new approach to chronic disease management for the 21st century", UK Dept of Health, 14/9/2001.

[78] Integrated Care Network "Bringing the NHS and Local Government together. Integrated working: a guide".

NOTE: Available at http://www.integratedcarenetwork.gov.uk/pub.php

[79] Wistow, G.: "The New Vision for Adult Social Care: Responses to a survey conducted by the Social Care Institute for Excellence, commissioned by the Department of Health". The Social Care Institute for Excellence, UK, 2004.

[80] Jennett, P.A., Affleck Hall, L. et al.: "The Socio-economic Impact of Telehealth: A Systematic Review". Journal of Telemedicine and Telecare, 9(6), 2003.

[81] Kelly, D: "Smart support at home: the integration of telecare technology with primary and community care systems", in The British Journal of Healthcare Computing & Information Management, April 2005, Vol. 22, No. 3 p19-21.

[82] Johnston, B., Wheeler, L., Deuser, J. and Sousa, K. H.: "Outcomes of the Kaiser Permanente Tele-Home Health Research Project", in Arch Fam Med, January 2000.

[83] Ellis, I: "Is Telehealth the Right Tool for Remote Communities? Improving health status in rural Australia". Contemporary Nurse, 2004, 16(3).

[84] Joint Venture of the Electronic Industries Alliance and the Electronic Industries Foundation: "Resource Guide for Accessible Design of Consumer Electronics", November 1996.

[85] Johansen. I, Breivik, E.: "Is teleradiology service in primary health care cost-effective?" (in Norwegian). Tidsskrift for den Norske Lægeforening 2004; 124(19):2490-2.

[86] ETSI EG 202 416: "Human Factors; User Interfaces; Setup procedure design guidelines for mobile terminals and e-services", draft version (under development).

[87] Curry, R.G., Trejo Tinoco, M., Wardle, D.: "Telecare: Using Information and Communication Technology to Support Independent Living by Older, Disabled and Vulnerable People".

NOTE: Available at http://www.icesdoh.org.uk/downloads/ICT-Older-People-July-2003.pdf.

[88] Comas-Herrera, A., Costa-Font, J., Gori, C. et al.: "The European study of long term care expenditure". Report to the European Commission, Employment and Social Affairs DG. Edited by Adelina Comas-Herrera and Raphael Wittenberg. PSSRU, LSE Health and Social Care, London School of Economics.

[89] ETSI EG 202 417: "Human Factors (HF); User education guidelines for mobile terminals and e-services", draft version (under development in June 2005).

[90] Arksey H.: "Access to Health Care for Carers: Intervention Evaluations". Supplementary Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO) 2003.

NOTE: Available at http://www.sdo.lshtm.ac.uk/pdf/access_arksey_suppl.pdf

[91] Shoval, S., Borenstein, J. and Koren, Y.: "The NavBelt-a computerized travel aid for the blind based on mobile robotics technology". IEEE Trans Biomed Eng, 45(11), 1376- 1386, 1998.

[92] Benjamin, J. M., Ali, N. A., and Schepis, A. F.: "A Laser Cane for the Blind". In Proceedings of the San Diego Biomedical Symposium. Vol 12, 53-57, 1973.

[93] CEN TC251, document N04-053: "Melvin Reynolds tutorial presentation on Point of Care Medical Devices standards".

NOTE: Available at http://www.centc251.org/TCMeet/doclist/doclist2004.htm

[94] Ravault, C. (ed.): "Impact sanitaire de la vague de chaleur d'août 2003 en France. Bilan et perspectives - Octobre 2003." Institut de veille sanitaire. ISBN 2-11-093923-0. CARACTERE (Aurillac), 2003.

[95] Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

[96] ETSI TR 102 202: "Human Factors (HF); Human Factors of work in call centres".

[97] Khazei A, Jarvis-Selinger S, Ho K, Lee A.: "An assessment of the telehealth needs and health-care priorities of Tanna Island: a remote, under-served and vulnerable population". Journal of Telemedicine and Telecare, 11(1), 35-40, 2005.

[98] Bice, S., Dever, G., Mukaida, L., Norton, S., and Samisone, J.: "Telemedicine and Telehealth in the Pacific Islands Region: A Survey of Applications, Experiments, and Issues". Proceedings of the Pacific Telecommunications Conference '96, 574-581, 1996.

[99] Bashshur R.L., Armstrong P.A., Youssef Z.I. "Telemedicine: explorations in the use of telecommunications in health care." Springfield, IL: C.C. Thomas; 1975:354.

[100] House, A.M., Roberts, J.M. "Telemedicine in Canada [1977]". Canadian Medical Association Journal, 117(4): 386-8, 1977.

[101] National Electrical Manufacturers Association (NEMA): "DICOM standard".

NOTE: Available at http://medical.nema.org/

[102] International Commission for Non-Ionising Radiation Protection (ICNIRP): "Guidelines for limiting exposure to time-varying electric, magnetic, and electromagnetic fields (up to 300GHz)". Health Physics 74(4), 494-522, 1998.

[103] UK Department of Health: "The NHS Improvement Plan: Putting people at the heart of public services" page 86, 2004.

NOTE: Available at http://www.dh.gov.uk/assetRoot/04/08/45/22/04084522.pdf

[104] Whitten, P.: "The state of Telecommunication Technologies to Enhance Older Adults' Access to Health Services". In Rogers, W. and Fisk, A.D. (ed.): "Human Factors Interventions for the Health Care of Older Adults", 121-147. Lawrence Erlbaum Ass. Publishing, Mahwah, NJ, 2001.

[105] Matsushita Electric Service: "Mimamori Net service (allows remote family members to check the status of the elderly living alone at home through mobile e-mail service)".

NOTE: Available at http://www.mew.co.jp/e-press/0204_0206/0209-01.htm

[106] European Commission. "Applied IST research addressing major societal and economic challenges. eInclusion Strategic Objectives".

NOTE: Available at http://www.cordis.lu/ist/workprogramme/wp0506_en/2_5_11.htm

[107] National UK Audit Office: "Ensuring the effective discharge of older patients from NHS acute hospitals". Report by the Controller and Auditor General HC 392, session 2002-2003: 12 February 2003.

[108] ISO 14971: "Medical devices. Application of risk management to medical devices".

[109] IEC/CD 62366: "Medical devices - Application of usability engineering to medical devices".

[110] ETSI EG 202 067: "Universal Communications Identifier (UCI); System framework".

[111] IEEE 802.15.1™ (2002): "Standard for wireless personal area networks adapted from the bluetooth specification".

# 3 Definitions and abbreviations

## 3.1 Definitions

For the purposes of the present document, the following terms and definitions apply:

**assistive technologies:** any product, instrument, equipment or technical system used by a disabled person to prevent, compensate, relieve or neutralize an impairment, disability or handicap

**assistive technology device:** device used by a disabled person to prevent, compensate, relieve or neutralize any resultant handicap and which has the ability to interface to an ICT device

**baby:** child, 0 to 1 years of age

**carer:** individual who provides care to the client, mediated through or assisted by the telecare service

NOTE: Carers and coordination agents will need to be able to use the telecare services efficiently and will have human factors needs that must be addressed.

**child:** person up to the age of 12 years

**client:** individual receiving the telecare service, to support independent living and/or using telecare services for the care of his or her own health

**coordinator (agent):** individual who coordinates the delivery of care through the use of the telecare service

NOTE: Carers and coordination agents will need to be able to use the telecare services efficiently and will have human factors needs that must be addressed.

**design for all:** design of products to be usable by all people, to the greatest extent possible, without the need for specialized adoption

**domiciliary (home) care:** care arranged by social services and delivered to persons in their own homes

NOTE: Can include assistance with personal care including washing, dressing, going to and getting out of bed, assistance with laundry, shopping and with a range of practical/domestic tasks.

**emergency service:** service, recognized as such by the EU Member State that provides immediate and rapid assistance in situations where there is a direct risk to life or limb, individual or public health or safety, to private or public property, or the environment, but not necessarily limited to these situations

**end user:** see **client, carer** and **coordination agent**

NOTE 1: Whilst clients are the primary end users of telecare services, the carers and coordination agents will need to be able to use the telecare services efficiently and will have human factor needs that must be addressed.

NOTE 2: Carers and coordination agents will need to be able to use the telecare services efficiently and will have human factors needs that must be addressed.

**function:** abstract concept of a particular piece of functionality in a device or service

**ICT devices and services:** devices or services for processing information and/or supporting communication, which has an interface to communicate with a user

**impairment:** any reduction or loss of psychological, physiological or anatomical function or structure of a user (environmental included)

**informal carers:** relatives, neighbours, friends or volunteers providing care for the person in need

**intelligent home:** see **smart house**

**mobility:** see **personal (user) mobility** and **service mobility**

**personal (user) mobility**: ability for the user to access personal services and data independent of the device and access network used (including user's fixed and mobile devices), while maintaining their personal communication environment

**residential care:** personal and/or nursing care that is provided to a person in a formally managed care home, in which the person is also provided with accommodation that includes appropriate staffing, meals, cleaning services, furnishings and equipment, for the provision of that care and accommodation

**service mobility:** possibility for services to be accessed and delivered independently of network, terminal or geographical location attributes

**smart house:** a house with a communication infrastructure, allowing interconnectivity of systems and devices in that home

**telecare:** the delivery of health and social care to individuals within the home or wider community, with the support of systems enabled by ICT

NOTE: See [33]. Additional components of the concept also include safety and security monitoring services and Electronic Assistive Technologies (EAT).

**terminal:** physical device which interfaces with a telecommunications network, and hence to a service provider, to enable access to a telecommunications service

NOTE: A terminal also provides an interface to the user to enable the interchange of control actions and information between the user and the terminal, network or service provider.

**usability:** effectiveness, efficiency and satisfaction with which specified users can achieve specified goals (tasks) in a particular environment

NOTE: It includes the concepts of learnability and flexibility.

**User Interface (UI):** physical interface through which a user communicates with a telecommunications terminal or via a terminal to a telecommunications service

NOTE: The communication is bi-directional in real time and the interface includes both control and display elements.

**user requirements:** requirements made by users, based on their needs and capabilities, on a telecare service and any of its supporting components, terminals and interfaces, in order to make use of this service in the easiest, safest, most efficient and most secure way

## 3.2 Abbreviations

For the purposes of the present document, the following abbreviations apply:

| | |
|---|---|
| ADL | Activities of Daily Living |
| ADSL | Asymmetric Digital Subscriber Line |
| AT | Assistive Technologies |
| EAT | Electronic Assistive Technologies |
| GP | General Practitioner (Medical Doctor) |
| GPRS | General Packet Radio Service |
| GSM | Global System for Mobile telecommunication |
| ICT | Information and Communication Technologies |
| IP | Internet Protocol (also known as TCI/IP) |
| IPv6 | Internet Protocol version 6 |
| ITU-T | International Telecommunications Union - Telecommunication standardization sector |
| MMI | Man Machine Interface |
| OECD | Organisation for Economic Co-operation and Development |
| P3P | Privacy Preferences Protocol |
| PIN | Personal Identity Number |
| RFID | Radio Frequency IDentification |
| SDSL | Symmetric Digital Subscriber Line |
| SMS | Short Message Services |
| UI | User Interface |

UMTS Universal Mobile Terrestrial System

NOTE: also known as 3G (Third Generation).

VoIP Voice over Internet Protocol
Wi-Fi Wireless Fidelity

NOTE: ISO/IEC local area network standard (IEEE 802.11 family).

Wi-Max IEEE 802.16 (common name)
WHO World Health Organization's

# 4 Telecare and its service provisioning elements

## 4.1 Definitions and approach

There are various definitions of telecare. One example is:

"Telecare is the interaction of an individual with electronic devices combined with a communication capability, to access or transmit health information or to provide or receive guidance or support on a health-related issue" [33].

For the purpose of the present document the definition of telecare is broadened to include social care but focused on services which directly involve the recipient of care, the client, and therefore differentiated from telemedicine such that:

***"Telecare involves the delivery of health and social care to individuals within the home or wider community, with the support of systems enabled by ICT [31]".***

Telecare refers to services that are delivered to an end user, in most cases a consumer- the client. Telecare can be expressed as a business-to-consumer service, where a health care business supplies services to the end user. In contrast, and for the purposes of clarity, Telemedicine can be defined as the use of ICT to support the transfer of information between care professionals to aid the support of a client (a business-to-business transaction model). In the present document we are concerned with telecare services delivered to end users.

Our definition of telecare has led us to refer to the client who is in receipt of care service, through the use of ICT, as the primary end-user. We also adopt the broader process model outlined by Baxter et al. [32]. They define a typical telecare system as having three distinct elements, as shown in figure 1.

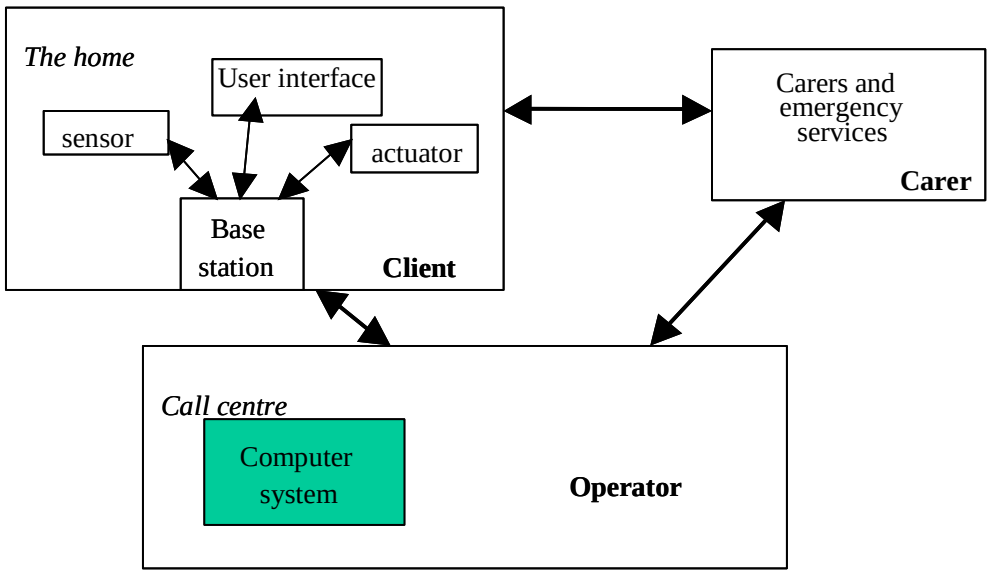



**Figure 1: A generic telecare system model**

In this model, the clients are generally considered to receive care services in their homes. The home will contain a number of sensors and perhaps other devices, such as display's and actuators which, where appropriate can communicate with the outside world either directly or via a base station or home hub. The data that is transmitted from the home might be raw sensor data, such as a blood sugar reading, or data from a set of movement sensors, alternatively the base station in the home may process the raw data and only issue high level calls for assistance or updates to a patient record.

The data from the home may be transmitted to a call centre operator, whose role is to monitor the client's status. The status monitoring function may be undertaken by an automated process in a computer system within the call centre with only anomalous behaviours or trends flagged to a human operator. The operator role is usually one of coordination. It is the operator who will make a judgement about if and when to involve a third party such as a clinician, carer, family member or the emergency services. In some situations, depending on the degree of intelligence and autonomy within the home installation, and the configuration of the service, the coordination role is not required and becomes subsumed into the functionality of the client's home system, in which case calls to third parties for assistance are made directly between the home and the clinician, carer or emergency services.

Telecare services will have many different configurations depending on the specific circumstances of the service provider and of the client. This will be influenced by the physical and cognitive capability of the client, the intelligence of the system, service provider requirements for automated or manual coordination and so on. However, the model in figure 1 is a general model that will apply in almost any circumstance. In some cases a single person may perform two roles; for example the person in the home can perform the client and the operator role - deciding for themselves if and when they need assistance from their care provider.

The model is not prescriptive, however, it is our intention throughout the present document to pay attention to the needs of all potential end-users of telecare systems and so we define three end user types:

- **clients:** those individuals who are receiving the telecare service to support their independent living;
- **carers:** those individuals who provide care to the client, mediated through or assisted by the telecare service; and
- **coordination agents:** those individuals who coordinate the delivery of care through the use of the telecare system.

Whilst clients are the primary end users of the system, the carers and coordination agents will need to be able to use the telecare systems efficiently and safely, in order to offer an effective service, and will therefore have human factor needs that must be addressed.

We have chosen to build our approach to telecare services on an extension to a framework proposed by Barlow et al [31]. They define a model of telecare services which includes information and communication, safety and security monitoring, personal health and activity monitoring and Electronic Assistive Technology (EAT).

Examples of the components within each of these four services are:

- information and communication;
- safety and security monitoring;
- personal monitoring; and
- Electronic Assistive Technology (EAT).

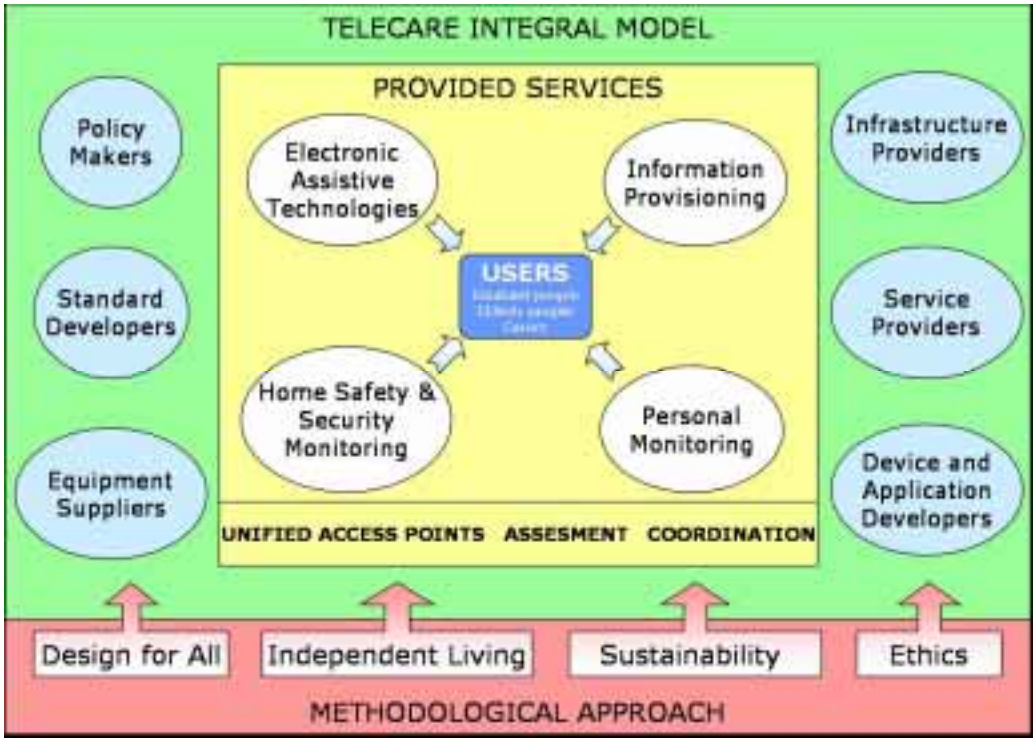



**Figure 2: A telecare service framework (integral model)**

Barlow et al have shown how these four components of telecare might fit together, centred on the client in the home. The extent of the service provision will be driven by the needs of the client and should be flexible enough to cope with short periods of intense requirement in one or more areas due to illness, or respite care needs etc. Whilst some elements of this service model are already well developed, such as safety monitoring through the community alarm services, little attention has been paid to the broader holistic view and the human factors issues associated with combining the elements in a seamless and effective manner for the client. Standards and voluntary codes of practice have been developed in some telecare service areas, but little work has been done on the issues associated with interoperability of the four different service elements.

In the present document, we survey each of the four specific telecare service provision elements, identify areas of commonality and areas of incompatibility and from this, make recommendations of what needs to be put place to ensure that all end users obtain a seamless suite of services.

## 4.2 Electronic assistive technology services

### 4.2.1 General

Accessibility and personal assistance are key factors in the provision of autonomy and independent living to people with disabilities. Accessibility to environments, services and products is achieved by two complementary approaches: "Design for All" and Assistive Technologies [34]:

- "Design for All" can be defined as the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.
- Assistive technology can be defined as any product, instrument, equipment or technical system used by a disabled person to prevent, compensate, relieve or neutralize an impairment, disability or handicap.

"Design for All" rather constitutes an ideal philosophy, as all products and services should be fully accessible to all users. This can not be considered a realistic goal, because of the wide range of user requirements and abilities, the limited available technology, etc. In practice, we adopt a "Design for the Majority" approach, within a trend pushing for a continuous reduction of the gap between human abilities and user interfaces of products and services, and consequently pushing for a continuous increase of the population percentage inside the "Majority".

When a "Design for All" solution is not already available, because it is not practical, possible or cost-effective to meet all requirements, assistive technologies offer technical interfaces to fill the gap between the UI of the device and the abilities of the user [1] and [39].

For the Department of Health of the UK, assistive technologies are part of the so-called community programme, and are considered as "equipment for older or disabled people that provides the gateway to their independence, dignity and self-esteem. It is central to effective rehabilitation; it improves quality of life; it enhances their life chances through education and employment; and it reduces morbidity at costs that are low compared to other forms of healthcare" [35]. These services are essential for the quality of life of many older or disabled people, and also for those who provide informal care.

The continuous evolution in the field of Information and Communications Technologies has created new ways of providing accessibility for people with disabilities. But at the same time, it is more and more difficult to distinguish assistive technology products from common consumer products.

"This debate is not new: many years ago, it dealt with the issue of dishwashers. Now the debate revolves around computers, mobile telephones, video telephones and smart house technology, among other things" [36].

TR 102 068 [1] includes a list of those assistive technologies which are included in the ISO 9999 classification system [52], and that have the potential to be interconnected to information and communication technology systems. Taking into account the scope of this report, attention is paid to the relation of electronic assistive technologies with telecare services. This relation could be categorized in two main groups:

- Assistive technologies supporting users' interaction with ICT elements of the telecare equipment.
- Integration within the telecare infrastructure of assistive technologies supporting users in their Activities of Daily Living (ADL).

### 4.2.2 Examples and scenarios

A few examples and scenarios of the use of assistive technologies for interacting with telecare equipment are provided below:

**User access to outputs generated by the system:** Notification of home alarms or incoming calls to people with visual or hearing impairments, reaching terminal displays by people with mobility impairments, perception of auditory or visual outputs in a videoconference session for people with hearing or visual impairments.

People with hearing loss will find it difficult to perceive auditory output from telecare terminals. Hearing aids could be coupled to the system output through a wireless connection.

**Users' ability to generate inputs expected by the service:** Audio communication for people with speech impairments, pushing alarm buttons for people with mobility, manipulation or dexterity deficiencies.

Wheelchair users may face difficulties to reach the telecare service controls: A hand-held terminal could be connected to the terminal via a wireless system; e.g. a joystick being used to drive the powered wheelchair could be used for this purpose.

**Users' ability to locate the service elements:** People with visual or cognitive impairments may have difficulties to locate the interaction elements of telecare equipment. Location of telecare equipment may be difficult for blind people.

As an example/scenario of **integration of ADL assistive technology with telecare systems**, the smart house concept is proposed.

**Environmental control systems and Smart Houses:** These are services that allow home appliances and devices to be controlled by users, accordingly to their abilities and preferences. Older people and people with disabilities face numerous difficulties when trying to use home devices with interfaces that very often do not suit their physical, sensory or cognitive abilities. The use of these services can be thought as a key element in the naturalization of their relationship with the home environment.

There are several international initiatives trying to create a mass-market adoption of such advanced services. Telecare and "smart house" solutions should seek integration by taking interoperability and compatibility issues into account, as they share common important targets in the fields of alarm management, information provisioning, accessibility/comfort, etc. "Smart Houses" (also known as "home systems") constitute the evolution of environmental control systems, and tend to integrate those functions in a single home ICT platform or gateway:

- Smart homes may provide usable, multimodal UIs to control complex home appliances, like control of heating or multimedia devices [72].
- Environmental control functionalities may also be integrated with the alarm management module of a telecare service.
- Smart homes may provide operational integration with assistive technologies (e.g. using the joystick or switch that is being used to drive the powered wheelchair for controlling home appliances).

The current proliferation of home systems is not necessarily synonymous with an improvement in the quality of life for their users, as an integral and comprehensive human factors approach is needed. However, there is some specific work done in this field [34], [47], [55] and [72].

Several research projects funded by the European Commission have dealt with home systems and human factors:

- HEPHAISTOS (TIDE-1004): User oriented, iterative design process applied to the creation of multimodal interfaces including evaluation with older people and disabled users.
- CASA (TIDE-1068): Application of USERFIT, a user centred design methodology, in home systems design and development.
- HOME (TIDE-3003): Multimodal UIs for home services including gesture recognition and access through mobile phone.
- NJORD (TIDE-4102): Development of a handbook, the NJORD-TIDE Evaluation Approach System, which supplies information about evaluation methodologies in domotic environments.

There also exist some ongoing initiatives in this field, which in part deal with user related issues:

- The SmartLab is part of the activities of The Swedish Handicap Institute. Knowledge, experience and equipment for this experiment is inherited from the former SmartBo project. The aim is to show how smart houses may support the independent living of older people and disabled people.
- ePerSpace (IST-506775) is a project in the VI Framework Programme. The main objective is to increase the user acceptance of networked audiovisual systems and applications at home and virtually anywhere by developing innovative interoperable value-added networked services and innovative personalized, value-added networked services. The project is expected to deal with personalization and user profile management issues.
- NEM is an industrial initiative aiming to ensure that Europe is among the world leaders in providing an improved quality of life offered by the explosion of opportunities in the area of Networked and Electronic Media (NEM). One of the driving objectives of this initiative is to safeguard consumer and citizen interests through promotion of open and interoperable systems. It will also analyse how the range of new networked and electronic media technologies can impact the quality of life of the EU citizen, and provide policy makers with options for coherent and effective policies.
- The CENELEC SmartHouse Project is an integral part of the European Commission's e-Europe 2005 Initiative. The aim of the project is to develop a European Smart House Code of Practice and to establish and operate a Smart House Open Forum. The project will coordinate with market players, consumers and other interested parties, to reach consensus on recommendations for future standardization work in the Smart House field. One of the project sections is devoted to UI issues.
- In the USA, the American National Standards Institute has issued the Project 1678 - ANSI/INCITS 389 Draft "Information Technology Protocol to Facilitate Operation of Information and Electronic Products through Remote and Alternative Interfaces and Intelligent Agents: Universal Remote Consol" This American National Standard is one in a series on the operation of information and electronic products through remote and alternative interfaces and intelligent agents. The goal of this standard is to provide a framework of components that combine to enable remote control of network-accessible electronic devices and services through a Universal Remote Console (URC).

- In the USA, and as a result of a joint venture of the Electronic Industries Alliance and the Electronic Industries Foundation, the "Resource Guide for Accessible Design of Consumer Electronics" was issued in 1996 [84]. The present document is intended to help designers in their efforts to make their products more accessible for people with functional limitations.

### 4.2.3 Providing integrated models

In order to ensure that users have access to assistive technologies in the best possible, accessible and flexible way, it is necessary to work in some other fields apart from the technological one. The Spanish National Centre for Personal Autonomy and Assistive Technologies (CEAPAT) uses the term "complementary measures" for those non-technical fields, which affect the design and development of technical aids, as well as the functioning and configuration of markets, background of professionals and users, their social and economic situation, and the standardization process [38].

The "Equipped for Action" initiative in the UK proposes an integral model for provision of technical aids. It is stressed that such a model requires partnerships between the statutory sector and the rest of the players involved. It will require the partners to "sign up" to a shared aim of improving information about and availability of the equipment that disabled people, older people and carers require for personal independence in their daily life [37].

Nordic countries have a common approach, although differences may appear from country to country [37]. Local authorities interact directly with citizens of assistive technologies (on a business-to-consumer basis), and also with county or central units for several specific tasks (business-to-business approach): managing users' applications, receiving some training or advice on sophisticated technologies, etc.

### 4.2.4 Searchable databases

Searchable databases ease the finding of appropriate assistive technologies, allowing searches by aid type, functionality, etc. Data about price, manufacturers and distributors are also very useful. Nevertheless, in general the selection of appropriate aids for specific users will require the combination of database searches with professional advice, product evaluations, etc.

The target audiences of these databases include people with disabilities, family members, service providers, educators, employers, et cetera.

These are some of the existing databases:

- The TechDis Accessibility Database provides an on-line resource of information about products which are available to assist those with disabilities. The resource is designed to provide information on assistive, adaptive and enabling technologies to the United Kingdom Higher and Further education sectors, http://www.techdis.ac.uk/.

- The Scandinavian countries all have searchable databases of available technical aids for the handicapped: Hjelpemiddeldatabasen, http://www.hjelpemiddeldatabasen.no/ (Norway), HIDA, http://www.hi.se/HIDA/default.shtm (Sweden), and Hjælpemiddelbasen, http://www.hmi-basen.dk/ (Denmark); the Finnish organization STAKES maintains the APUDATA database, which includes services and organizations in the field of assistive technology [45] and http://www.stakes.fi/apudata; the State Social Security Institute of Iceland has also set up a database for the provision of assistive technology.

- The CEAPAT (Spanish National Centre for Personal Autonomy and Assistive Technologies), part of the Ministry of Labour and Social Affairs, has developed a searchable database, as a tool for disabled people and rehabilitation professionals http://www.catalogo-ceapat.org/

- ABLEDATA is a USA government funded project whose primary mission is to provide information on assistive technology and rehabilitation equipment available from domestic and international sources to consumers, organizations, professionals, and caregivers http://www.abledata.com/

- ASSISTIVETECH.NET created by the Georgia Tech Centre for Assistive Technology and Environmental Access (CATEA) located in Atlanta, Georgia, USA http://www.assistivetech.net/

### 4.2.5 Virtual stores

In the UK, the Department of Health has launched the Community Equipment Virtual Store (CEVS), with the aim of reducing the delays in the provision of special equipment and providing advice for specific users. This applies especially to equipment for children, where prompt provision may be vital to their development. Children's equipment is usually adjustable and adaptable and is therefore not necessarily specific to just one child: this could make delivery possible within a matter of days rather than weeks or months. On the top of that, this system may solve a problem detected by Community Equipment Stores (CES): as paediatric equipment is not generally held as core stock, returned items often remain unused in community equipment stores.

Although the website is available for anyone with Internet access (at http://www.icesdoh.org/cevs), all enquiries should be service-to-service, store-to-store, professional-to-professional, or a combination of these.

### 4.2.6 Future development

The aging of the world population will require a significant development of the Assistive Technology (AT) sector: "Growth in the number of older people in the populations of countries in the United States, Europe, Asia, and elsewhere suggest that there will be a strong, steady increase in demand over the next several decades for a broad spectrum of EAT devices from hearing aids and canes to advanced wheelchairs, specially equipped automobiles, and personal communications devices" [40].

Another driver for the growth of EAT is the involvement of new technologies in this field, improving hardware (more computer power, availability of low-cost microelectronic components), software and creating new technological paradigms like Ambient Intelligence. This will result both in improvements in the capabilities of today's assistive technology devices and in the creation of new products.

## 4.3 Home safety and security monitoring services

### 4.3.1 General

The concept of telecare should not be limited to medical aspects, but should include also ICT-based monitoring and control of environmental parameters related to the general well-being of those in need of care. Some examples are services for monitoring the home environment, means for protecting inhabitants from accidents, and burglar alarms. It also should comprise ICT-based assistive technologies for impaired people outside of their homes, like the "Eye-phone" [17] whereby a blind person equipped with a mobile cam can get help by transmitting an image to a remotely located viewer.

A mix of commercial agents, bodies set up by the government or the local authorities and/or infrastructure suppliers (telephone, water/electricity, gas) deliver services for telemonitoring and control. These suppliers must be able to cooperate to fully realize the potential benefits of telemonitoring and control. There are also independent brokers that act on behalf of the user, to bring together suppliers of services for enhanced effectiveness and to realize possible synergies [23].

### 4.3.2 Examples and scenarios

**Scenario 1: Temperature monitoring and warning**

It will be fairly straightforward to extend systems for heating control so as to monitor and react to extremes of temperature, either cold spells during winter, or summer hot spells (like in the Paris region in August 2003, when the excess mortality attributed to overheating was close to 15 000 [94]).

User aspects of extending heating control to temperature monitoring in a broad sense range from how easy it is to activate (or deactivate) the monitoring, what temperature levels should be considered hazardous, and how an alarm is to be treated once it is raised.

Taking this concept still further, temperature control can be coupled to sensors of activity and of presence. To realize this, there must be both a UI that makes this possible and easy to set up, and there must be standards for connecting equipment from different suppliers together.

**Scenario 2: Home security**

Several home installations and appliances are inherently risky: a leaky gas stove, an electric stove or iron left on accidentally, old electrical circuitry. Some of these risks can be reduced by fairly simple electromechanical means, but they can also be controlled, monitored and warned about using ICT. Examples: Raise an alarm when the instantaneous gas or electricity consumption has been above a steady-state mean for a certain period (stove forgotten); when the mean gas usage suddenly increases (leakage); automated insulation testing to reveal faults in the electrical wiring.

In several European countries, a number of demonstration projects with smart houses give a broad experience of the various aspects of real practice implementation at the lowest costs. An overview of projects in Belgium, Norway, Germany, UK, and the Netherlands can be found in [57].

People with dementia, suffering from Alzheimer's disease or who are otherwise confused or cannot easily take care of themselves may need special safety precautions to protect them from the dangers of the normal home environment. A safety checklist for the home is presented in [21]. Most of the items are not particularly IT related (set limits on hot water temperature, avoid slippery floor, ensure adequate lighting etc.), but they point to areas where external surveillance can be helpful. Furthermore, people with dementia may leave their homes at odd hours, and have trouble finding their way back. Unobtrusive wearable positioning devices may be of help for this group e.g. [22]. Several companies are now trying GPS or GSM-based positioning devices, e.g., PlaneTrak extending their car GPS technology with the products Kidangel (to help parents locate a child), and Parentrak (to track the location of aging adults/parents).

Other location technologies are RFID, with possibilities for subcutaneous placement (VeriChip scanner-activated, subdermal passive RFID http://www.verichipcorp.com/ and Trovan human implantable transponders, see http://www.trovan.com/products100ih.htm).

**Scenario 3: Environmental threats**

People suffering from asthma, pollen allergy or other dysfunction of the airways could be warned if the air pollution, pollen level etc. exceed certain levels. Such warnings are now given as broadcast messages, (radio, TV, journals), but could easily be targeted directly over GSM to those affected, perhaps even with personalized and settable warning levels, pollen types etc.

Another environmental threat is tornados, earthquakes and tsunamis. These are rare events that pertain only to particular regions, but which can be catastrophic when they hit. It is often possible to predict such events, giving the inhabitants some hours or even days to take precautionary measures or to evacuate. Disabled and impaired persons should in such cases be especially targeted and warned, and the surveillance system should make sure that the warning has been received and acted upon.

**Scenario 4: Multifunctional sensor device for mobile use**

Telecare services involving the temporary use of sensors in addition to the home environment (e.g. in cars, hotel rooms and vacation houses) will benefit from the availability of multifunctional, mobile mass-market sensory devices with a built-in communication capability. Compact units with integrated sensors and modules are becoming available (e.g. http://www.ayone.net/, and offer capabilities to "…see, hear and feel the surrounding environment and monitor temperature and motion" and inform about changes.

### 4.3.3 Precautions, reliability and fail-safe operation

Advanced home environment sensors and parameter measurements as described above will only be widely accepted if important usability factors such as UIs and generic UI elements, control by remote personnel and dependability aspects are properly handled. For example, the purpose and functionality of a service should be easy to understand and control its parameters. Also, if the end user does not want to (or is unable to) control the device(s), it should be possible to operate them from a distance, by a care centre or an informal carer. Systems that can be life critical should be very dependable, meaning that the design should support fail-safe functionality. In addition, redundant options should be provided [24].

### 4.3.4 Equipment integration, interoperability and user confidence

There can be substantial gains in functionality by combining safety monitoring and control devices with other sensors that monitor the user and the general environment. To avoid market monopoly and to widen the competition, standards for data exchange must be agreed upon. However, the collection of information from many sources entails obvious privacy risks for the individual. It is imperative that the information gathered about the individual is safeguarded against misuse, intentional or accidental.

The moral, juridical, ethical and confidentiality requirements involved when deploying safety monitoring and control devices should be clearly defined. Both the end user and the informal carers must take part in selecting an appropriate level of security and warnings versus privacy and false alarms, what to do in case of a raised alarm, etc.

### 4.3.5 Examples of commercial surveillance services

There is a plethora of commercial, ICT-based services for home safety monitoring and accident prevention, ranging from the very simple to the very sophisticated. Some examples are:

- **Smoke/fire alarms:** Local warnings and automatic call-in to alarm centre. Alarm deactivated by calling in. Low cost, simple to install.
- **Burglar alarm:** Automatic call-in to alarm centre. Alarm deactivated by calling in. Low cost, simple to install.
- **Telephone Notification System:** Dial-out monitors for temperature, power and humidity, to detect faulty furnace, air conditioner, or electricity failure. Medium cost, medium complex installation.
- **Emergency button:** One-press button for activating alarm and signalling a monitoring centre (the same technology as for medical emergencies).
- **Environmental surveillance:** CO detectors, radon detectors, detection of other hazardous or nausive gases; local alarms.

The communication technology is mostly based on fixed, analogue telephone, but GSM-based services are gradually being offered where appropriate. Some service suppliers use the power line as a signal carrier. The in-house wiring is mostly proprietary, or can use one of several industrial instrumentation-bus standards. Low-power, short-range radio transmission can also be used for signal transmission; however this raises a problem of supplying power to the sensor.

### 4.3.6 Future development

Going one step further from the single-sensor system, researchers are trying out integrated systems for assessment of personal well-being, where the signals from several sensors are collected and subjected to sophisticated trend and correlation analysis. The availability of a continuous personal health status opens the possibility to provide a continuum of care, tailored to the status of the person cared for.

On the level of the health care providers, several initiatives throughout Europe try to integrate the different information databases and the different bodies that together are involved in the care of a person, at home or in an institution. The initiatives have names such as health grid, grid infrastructure, health network, telemedicine network etc., and aim to streamline and better target the health care delivery while making efficient use of resources and avoiding double work. In this respect it is important to integrate and coordinate the work of the socially-oriented and medically-oriented care providers.

On the level of the communications infrastructure, the proliferation of ubiquitous, digital, always-on, wireless communication channels, like GPRS for the mobile user, WI-Fi in-house or in targeted public zones, as well as UMTS and the emerging Wi-Max technologies, open the possibility for continuous health care irrespective of time and place.

## 4.4 Information, communication and educational services

### 4.4.1 General

Information, communication and educational services play an increasingly important role in the delivery of healthcare services. With the technical development offering seamless and more continuous access to broadband networks, the vision of a world where ICT resources around us improve the quality of our lives is more realistic than ever.

Delivering healthcare and social services over time and distance is not a new concept in telecare. However, one of the greatest potential benefits of new technology is the opportunity to improve the quality of care by making information faster and more easily available to clients, specialist advice and support more accessible to GPs and other professionals, and by bringing services closer to people's homes.

Information, communication and educational services can improve local access to distant services and specialist advice, offer on-line health advice services to clients and carers, access to self-help groups, professional or other web-based medical advice services, virtual visits, reminders, and thereby provide more continuous service availability.

In order to be able to access and use such services that cannot usually operate purely within the home, the client must meet certain requirements: most often, a telephone or a PC must be used to gain access to these information, communication and educational services. These will immediately involve a variety of generic usability requirements to be met. Furthermore, as the clients are often older people, issues of vision, sight, hearing and cognitive capacities are raised. In other cases, less literate users may experience considerable difficulties.

Finally, some of these applications raise important questions about their appropriateness in particular circumstances. Healthcare services involve complex social and emotional relationships, and the introduction of technology must take this into consideration. It is important that telecare services do not lead to new forms of social isolation. Also, in some cases legal and ethical questions may arise, such as in the use of videotelephony by a remote party to see into someone else's home. For these reasons, there is a need to ensure that comprehensive social and privacy assessments are made of the usage of technology for these purposes. Ethical guidelines also need to be provided and followed.

The most basic kind of telecare services relate to information provisioning. Voice-centric telecare telephony services are the most widely spread and well established application area and user requirements applicable to telephony services are applicable. These can lead to:

- improved service efficiency and can lead to considerable costs savings, provide instant and location-independent access to, in many cases, nation-wide access numbers;
- effective healthcare staff resource management, as call centres can easily be deployed to remote areas or regions offering benefits of subsidies, lower costs, or necessary language coverage and other multicultural issues; and
- lowered waiting and answering times and thereby, a decreased risk management.

Remote diagnostics and monitoring may have relevance both in emergency situations and in situations where mobility is a problem, either for the older or disabled person or for the service provider. Tele-consultation can be based simply on the availability of information on the Web, discussions over the telephone or can involve videotelephony to enable some level of visual appraisal of the problem. Remote monitoring of biomedical indicators like blood pressure is already being used in some cases and there are experiments using videotelephony to monitor biomechanical performance after hip replacement operations.

Other successful application areas for the provision of information services is through the Internet-enabled World Wide Web in countries where the penetration of household Internet connections and Web use rates are considerable. There is a variety of available Web sites, providing health-related information services, on-line tutorials and other sources to self-information or prescription services.

However, there are some issues of relevance to take into consideration:

- In the enlarged EU (EU25), only 47 % of individuals aged from 16 to 74 used the Internet during the first quarter of 2004 [63].
- Access to the Internet and the Web is decreasing with the age. Also, more men than women used the Internet, and more young people than old.
- Mobile communication services are now a mass market: in 2004, at least 80 % of EU citizens were using them. The number of broadband access lines deployed across the EU rose by over 72 % in the year to mid-2004, to 29,6 million, when the share of the EU population actually using broadband services was 6,5 % (7,6 % in the pre-accession EU 15 Member States). Broadband take-up is growing so fast that the latest data, compiled since the Communication was finalized, suggests that 8,8 % of the EU population now has a fixed broadband connection.
- Often limited (or even restricted) Web accessibility, due to limitations caused by the insufficient capabilities of supported by the UI. Most usually, the information is only offered as text-based information but can easily be extended to e.g. spoken text (e.g. the ReadSpeaker application will read Web pages, using text-to-speech synthesis www.tillganglighetsteknik.se).
- Aspects relating to the credibility of the source, privacy and other information safety issues.

"Client- managed care" are telecare services where telecommunications facilities support the client in taking a more active role in organizing and booking the care services needed. Opportunities for respite for family carers (e.g. for temporary relief from the responsibility for care) are also important in order to promote carer well-being and a good quality of care, and to encourage carers to continue to provide care. Telecommunications provide important opportunities in this area, for example, through the social alarm systems mentioned above and the possibility of monitoring the well-being or whereabouts of a person in need of care.

Finally, fixed and 3G-enabled mobile videotelephony is beginning to be used to provide a more advanced social alarm service, to deliver physiotherapy and other training, and as a more general vehicle for social contact and support for older people.

### 4.4.2 Examples and scenarios

One popular and most basic service offered is around-the-clock medical advices over the telephone, in some EU/EFTA member states reached through one and the same toll-free number. These services offer not only obvious benefits to the clients but also a considerable cost reduction to health care providers: in Sweden, the cost for such a call is estimated to 8 Euros, considerably lower than a visit to the doctor. Other services offered include prescription prolongations through the web or consulting and advisory services.

**Medical e-prescriptions** were introduced in Sweden in 2000. Four years later, every third medical prescription was sent electronically from the prescribing GP to a pharmacy www.e-receptstockholm.se. This decreases the risk for loosing the prescription including risks for falsifications, the administrative burden, the cost, the difficulties relating to unclear handwriting styles and the risk of errors and increases the reliability and nationwide flexibility of the system.

**Networks for elderly citizens**, with the goal to introduce older people to the use and benefits of the Web- e.g. SeniorNet www.seniornet.se, providing information about rights, best practices and other advice.

The ACTION EU-funded project deals with telematic support for carers and **telecare in practice** (it is a telecare initiative, focusing on carers of older people http://jhi.sagepub.com/cgi/content/abstract/7/1/41).

The EU-funded CONFIDENT IST Project 2000-27600 addresses older people and disabled people who use a PC-based system to design their **personal assistance**, according to their preferences. The system also provides remote monitoring of home accidents (through smoke detectors) and personal status (through a wrist wearable device detecting abnormal pulse). The system also allows users (both clients and formal/informal carers) to request services like transport service.

A number of initiatives under the EU's TIDE programme developed new ways of providing on-line information to disabled people and older people about social and health care services.

In rural Ireland, the IMSAS project has developed a prototype service to deliver information to older or disabled users, such as information about changes in the visiting schedule of care personnel or warnings about dangerous weather conditions. In this case, one of the main challenges is to be able to provide individualized information for each client. For the experimental prototype, the TV set and the Internet are being used to deliver the messages.

In the Italian city of Genova, the INSIDE project has developed a one-stop-shop for information and advice about health and social services. In this case, one of the main challenges is to help people to find the particular support that they need amidst a complex array of services and service providers. The one-stop-shop takes phone call queries from older people and their family carers, and uses relational database systems to identify appropriate solutions or appropriate referrals.

The Finnish trials were carried out under the APPSN and TELECOMMUNITY projects of the EU's RACE programme. Services were set up in three areas - Helsinki, Tampere and Kuusamo - and 32 households with older and disabled occupants were connected. The technology in the home consisted of a safety telephone, a standard 21" TV screen, a video camera and, where desired, a wrist-watch-type remote activator. The user just had to press a single button to activate a videophone call. An interesting feature of the approach was the use of Cable TV networks to carry the videotelephony, a solution that could be replicated in the many regions of Europe that are already cabled.

In Frankfurt in Germany, in conjunction with the RACE projects, the social services have been experimenting with a range of services based on videophones. One on-going project ("Haus-Tele-Dienst") offers the following services - video alarm service, access to information and counselling, remote monitoring and care, training and exercise programmes and support for carers - all based on video-telephony.

Experiments with videotelephony for older people have also taken place in Belgium. The municipality of Kortrijk, supported by the EU's Telematics Programme, has connected videophones in the homes of older people to a service centre, using the Cable TV network. The videotelephony facility allows older people to access social services at a distance and enables new forms of security and monitoring services to be provided.

Details and information on some of the telecare systems currently available in the UK can be found in table 1.

**Table 1: Telecare systems currently available in the UK**

| | |
|---|---|
| BT | www.bt.com/homemonitoring |
| Tunstall | www.tunstallgroup.com |
| Attendo | www.attendo.se |
| Jontek | www.jontek.com |
| Tynetec | www.tynetec.co.uk |
| Vivatec | www.vivatec.co.uk |
| Initial | www.iess.co.uk |
| Docobo | www.docobo.co.uk |
| Nestor | www.primecare.uk.net |
| Huntleigh Healthcare | www.huntleigh-healthcare.com |
| Cardionetics | www.cardionetics.com |

### 4.4.3 Future development

Connectivity and interoperability between telecommunications networks, personal computing, the Internet and ever-smarter mobile devices and services offer enormous potential for improving life, if used as intended and used by all.

With the advent of accessible, always-on personal, digital information and communication technologies, users raise their general level of knowledge and experience. This will lead to a more easy, quick and reliable deployment of telecare services.

The above mentioned development is considered an enabler to the delivery of information, communication and educational services, reachable and controllable through e.g. multimodal UIs accessed through smart terminals, relying upon mobile access provided through 3G systems with Europe-wide roaming.

## 4.5 Personal monitoring services

### 4.5.1 General

Personal monitoring services fall into two general areas: monitoring of physiology and monitoring of activities of daily living. Typically, monitoring of physiology requires that the client uses a sensor device to acquire a measurement of one or more physiological parameter for upload to a local, or remotely hosted, electronic patient record. This can include continuous collection of data from a wearable device such as wrist based pulse monitor, or more often periodic measurement of a specific parameter at set intervals during the day, using a discrete measurement device. The data from such systems will either be kept local to the client or used by the client to optimize their coping strategies, or for clients who require assistance to optimize their coping strategy a service provider can make the data available to a clinician for review. The clinician will usually be alerted if the physiological variable is outside of preset threshold values, and will initiate some form of intervention. This is a growing sector with many device manufacturers developing sensors that can communicate over proprietary interfaces, which may be wired, or wireless. There are also many companies who now offer some degree of monitoring services, often acting as intermediaries between the client and their usual care provider. Such services have been developed to tackle major chronic diseases such as diabetes, asthma etc.

Monitoring of activities of daily living is usually based on the use of sensors distributed around the environment of a client's home. A typical installation might include infra-red movement sensors placed in every room in the house, and transition areas such as hall ways and landings, plus proximity switches on entrance and exit doors and some appliances such as refrigerators and cupboards. Some installations are more comprehensive with additional sensors associated with bed occupancy, chair occupancy, toilet usage, bath or shower usage etc.

The principle of operation of such systems is that as the client within the home goes about their daily lives they will cause data to be generated from movement sensors, furniture occupancy sensors etc. The data from such sensors can be collected and analysed to infer the activities that a client is undertaking. Such systems are therefore able to invoke "rule sets" or models associated with the activities of daily living of an individual and monitor behaviour against these. Some system use manually coded rule sets based on the views of the client and/or the carer, others attempt to learn the behaviour patterns of the client over time and establish a "normal" profile automatically. Any departure in activity by the client from the model will generate an alert by the system indicating a potential cause for concern. Often such alerts will be false negative, in that the client has changed behaviour intentionally, for example by sitting quietly watching sport on TV for unusually long periods of time. Some monitoring systems will attempt to validate the cause for concern by allowing the client to cancel the alert through the use of a cancel device in the home, or through some automated voice system delivered over the telephone line. If the alert is not cancelled by the client within a pre-determined time period the system will usually escalate the alert to an alarm that is passed either to a service provider coordination agent or directly to an informal carer.

It is thought that changes in the well-being of an individual will manifest as subtle changes in the daily routines of the client, and therefore early warning of a pending crisis could be observed through trend analysis of this lifestyle data. Measurements of the client's ability to carry out activities of daily living might be used by social carer providers to make a judgement about the well-being of an individual, and whether some early intervention may be required in order to prevent a crisis which might otherwise occur in the future.

### 4.5.2 Examples and scenarios

Remote physiology monitoring services have existed for some years and are most well developed in the USA, but there are examples of services in Europe and Asia. Many services have combined physiology monitoring with video interaction between a carer and the client or between a co-ordinator and the client. A few examples of early trials follow:

**Kaiser Permanente Trial**

Between May 1996 and October 1997 the Kaiser Permanente Medical Centre in California, USA conducted a randomized controlled trial of remote video tele-consultations to the home. A total of 212 patients were assigned into either the intervention group or the control group. The patients were all suffering from recognized clinical conditions that would normally require significant outpatient attendance. The conditions included chronic obstructive pulmonary disease, cancer, diabetes, anxiety and wound care. The trial compared three quality of care indicators between the groups, and also contained a cost benefit analysis. Remote tele-consultation was shown to be effective, well received by clients, capable of maintaining quality of care and of achieving cost reductions. Cost savings were realized by reduced hospital costs associated with day visits in the group with the home tele-consultation equipment. The mean length of time for consultations during the trial was 45 minutes for a standard face to face visit and 18 minutes for a remote video visit. The trial used American TeleCare Inc. home telemonitoring equipment over PSTN [82].

**VNS Trial in Maine and New Hampshire**

In September 2002 a trial of home tele-consultation by the US Visiting Nurse Service (VNS) was reported. The Rural Utilities Office of the US Dept of Agriculture funded the trial for one year, beginning September 2001. The trial was focused on the meeting the needs of geographically isolated, chronically ill older people in southern Maine and New Hampshire. The trial used American TeleCare Inc equipment over PSTN, allowing a distant nurse to gather vital signs information and to make subjective assessment of the client through video and audio interaction. Cost benefit and quality of service data has not been reported, however, VNS have stated that they intend to move the project from pilot to full implementation with the aid of another grant by the Rural Utilities Office http://www.americantelecare.com/aboutus_PR_Collins.html.

**Remote dialysis service in Norway and Sweden**

There is an ongoing project in Norway for surveying patients during haemodialysis using video conference technology. Currently the clients travel to a small local health centre (Otta) instead of having to travel to a central hospital (Lillehammer). It is envisaged that the service may be extended to monitoring the treatment of clients at home. The University hospital of Lund (Sweden) has several patients performing haemodialysis at home, but currently without remote monitoring.

**March Networks Home Telecare Pilot**

In April 2002, the company March Networks reported that 95,5 % of patients in Canada's largest home telecare pilot were satisfied with the home tele-consultation service. The pilot was conducted between August 2001 and February 2002, involving 78 patients suffering from chronic diseases including cardiac and respiratory illnesses and cancer. The technology was provided by March Networks and used the home TV as the primary UI combined with a lightweight wireless monitoring device for vital signs such as BP, temperature, weight, blood oxygen saturation, etc. The tele-consultations lasted an average of 11 minutes and occurred twice per week. The system was used to substitute for face to face home healthcare visits made by nurses to the client's homes, significant cost savings were demonstrated whilst quality of outcomes were maintained.

The March Networks service was comprised of three elements: a home unit, the nursing station and the network application. The home unit included the client's own TV, a camera and a gateway that provides broadband connectivity. The nursing station was comprised of a laptop or desktop computer equipped with a web browser, a camera and speaker phone capability. The network application is the software that managed the remote visits and the collection of data and resides with an Application Service Provider (ASP). Further information is available at http://www.marchhealthcare.com/.

**American TeleCare Inc.**

American telecare began work on home telecare in 1993. The company now markets a range of video client stations: FDA approved Telemedicine monitoring systems that incorporate real-time bi-directional video and audio with integrated electronic medical peripherals that enable clinicians to conduct remote examinations of patients, such as an electronic stethoscope, BP monitor, etc. The American telecare service uses fixed, public network connectivity and has been used in the majority of home tele-consultation programmes in the US and is recognized as the industry leader in the US. Further examples of the use of American Telecare Inc equipment in home tele-consultations can be found at http://www.americantelecare.com/index.html.

More recently services have evolved to incorporate store and forward systems for the support of those with chronic disease and environmental monitoring. Some examples of systems to support chronic disease sufferers through offering monitoring technologies, access to clinical information databases, Internet-enabled decision support tools, health management programs and content development tools can be found at http://www.getcare.com/learn/monitoring.shtml.

**Vivago Wristcare**

Developed by the Finnish healthcare technology company, IST Oy, Wristcare is a wrist watch format device that continuously monitors physiological signs, changes in the user's normal activity and overall well-being. The device learns the user's normal activity level by measuring skin temperature, skin conductivity and micro and macro movement. If any unusual activity is detected, it will transmit alarms via phone to carers or to a 24-hour call centre http://www.istsec.fi/.

**Activity Monitoring**

West Lothian Council in Scotland have pioneered the large scale deployment of "SMART" sensors in up to 1700 homes to provide protection from intruders and other potentially dangerous situations. Movement sensors, fall detectors, flood alerts, smoke detectors and temperature extreme sensors are set up around the home and connected to the West Lothian Careline, where trained operators provide 24 hour assistance. The operators are able to identify the nature and location of the alert and contact the relevant source of help, be it doctors, emergency services, family, or West Lothian's own home safety team [81].

There have also been trials of systems to support the independence of older people in the US by relaying data associated with activity events which then translate into an understanding of how a client is managing in their home environment, for example see http://www.agingtech.org/item.aspx?id=67&cat=1&CA=1.

"Technology for Long Term Care" is a Web resource for professionals engaged in planning, designing, managing, researching, and care giving in long-term care settings. This site focuses on technologies related to important care issues including: fall prevention/detection, wander management, assistance call systems and incontinence management- see http://www.techforltc.org.

**EU IST FP5 Research projects**

There have been a number of relevant research projects supported by the EU Fifth Framework IST programme, such as:

- SILC, Supporting Independently Living Citizens, development of wrist-worn system to increase safety and independence of older and disabled citizens. IST Project 2000-27524.

- AMON, Advanced care and alert portable telemedical MONitor - IST Project 2000-25239.
- doc@Home, Telecare Project - IST Project 2000-25363/75363.
- SeniorWatch, Market study about the specific IST needs of older and disabled people - IST Project 1999-29086.
- T e l e C A R E, A Multi-Agent Tele-Supervision System for Elderly Care - IST Project 2000-27607.
- TelemediCare, IST Project 1999-10754.
- Confident, IST Project 2000-27600.
- MobiHealth, IST Project 2001-36006.

### 4.5.3 Overview of technologies and standards

The US based Telemedicine Information Exchange (http://tie.telemed.org/), created and maintained by the Telemedicine Research Centre with major support from the National Library of Medicine, lists over 80 vendors of home telehealth and telemedicine systems. Some of the vendors have been operating for more than a decade, initially using analogue PSTN systems. Many such companies have developed proprietary approaches to interfaces and data handling.

The Mobile Healthcare Alliance (MoHCA, http://www.mohca.org/) is an industry organization focused on mobile health information. Open to users, healthcare organizations, vendors, and others with an interest in mobile health, it provides an open forum for exchanging ideas, promoting learning, and sharing solution approaches for the management and security of health information in this arena. MoHCA supports identification of healthcare requirements, establishes recommendations for best practices, and promotes the development and use of accredited wireless standards.

The Technical Committee for Medical Informatics, TC251 of the European Committee for Standardization (CEN), established a project team (CEN/TC251/PT5-021) to standardize the representation of digitized biomedical signals, measurements, events and alarms, called vital signs in this context. The intended application areas of this standard proposal are found in the equipment used in intensive care, anaesthesia, neurophysiologic measurement laboratories, sleep laboratories etc. The goal in this work was to enable interoperability between the real time computer systems of different manufacturers also in time critical applications in hospitals, e.g. plug and play. A pre-standard was published in 2000. The main content of this CEN pre-standard has been distributed into the globally harmonized ISO/IEEE 11073-series [43], covering all point-of-care medical device communications. [43] and [93]. Standards for data exchange between devices, and definitions and support of ontologies between services [93] should be further developed.

The majority of today's short-range wireless systems aimed at indoor use and considered potential candidates for health care applications operate in the 2,4 to 2,48GHz ISM band (Industrial, Scientific and Medical). This is a regulated but licence-exempt band that was established some years ago for the development and deployment of wireless technologies. The regulatory requirements to operate in this band define the "controlled" elements, such as carrier frequency, power, antenna gain etc. Any system that complies with these requirements can operate within the band without any need to apply for permission. This means that these systems must be designed to be highly resilient and able to tolerate the potentially intense interference from other nearby systems, and the high likelihood of data packets being transmitted at the same instant, causing blocking and packet loss etc. All of this is made practicable primarily through wireless protocol standards such as the Wi-Fi family and others. Without these standards and the highly selective radio front-ends that are available today, reliable operation in the ISM band would by now be impossible because of the density of users now occupying the band. Nevertheless, care is required in deploying these systems because interference and blocking can still reach a level in extreme cases where even the best of today's protocols are insufficiently robust. There is a considerable amount of work currently ongoing in ISO/IEEE 11073 [43] (although mainly with a US focus at present), examining the use of RF for medical device communication. This has necessitated work with Wi-Fi 802.11e to attempt re-prioritization of QoS.

Bluetooth short range wireless systems operate in this band and comply with its own proprietary standard developed by the Bluetooth consortium (www.bluetooth.org), however it is also compliant with the IEEE 802.15.1 [111] standard. A key feature of this standard is the ability to self organize in an ad-hoc fashion, which is not the case with wireless LAN. Bluetooth allows 8-node networks, called pico-nets, to be created autonomously when Bluetooth devices come within range of each other. This is ideal for deploying health care sensor networks, although the upper limit of 8 may be inadequate in many circumstances. Unfortunately Bluetooth, like wireless LAN, has a relatively slow wake-up and so is not necessarily suited to the sporadic nature of sensors and their data.

Another 2,4 GHz ISM band scheme to emerge recently is Zigbee (www.zigbee.org). Zigbee complies with the IEEE 802.15.4™ standard and so has similarities with Bluetooth (802.15.1), such as the ability to form self organizing ad-hoc networks autonomously. However, there are profound differences between Zigbee and Bluetooth. Zigbee supports up to 65 534 nodes, which effectively means that it has no upper limit for all practical purposes. In addition Zigbee affords a longer battery life and greater radio range (30m) than Bluetooth. Its 250kbit/s data rate, although slower than Bluetooth, is adequate for the majority of health care applications of current interest. Zigbee is particularly suited for use in wireless sensor networks because of its very short wake-up time after long periods in an idle state.

In 1999 the 869 MHz band was set aside specifically for social alarm systems such as health monitors, wireless panic buttons, etc. Manufacturers of wireless health care systems are beginning to exploit this band because of its low occupancy compared with the 2,4 GHz ISM band. This new frequency is close to the frequency allocated to security systems. This band at 868 MHz is likely to be populated by increasing numbers of devices in the future. Its proximity to the telecare frequency should encourage telecare equipment manufacturers and users to insist on using Class 1 receivers to ensure adequate rejection of signals from other bands.

Other frequency bands of interest to indoor health care applications are 418 MHz and 433 MHz. These were formerly known as the Telemetry bands in the UK and, as the name suggests, were set aside for use in wireless telemetry systems such as remote sensors, wireless data loggers, etc. The 433 MHz band has been used in the UK for the past 5 or 6 years as a replacement for the original 418 MHz band which is no longer allowed. This brings it into line with the rest of Europe and this band is used for a wide range of signalling applications from remote controls for cars through to radio doorbells. Also in the US, the Medical Implant Communications Service (MICS) 402 to 405 MHz frequency band was allocated in 1999 as an ultra-low power, unlicensed, mobile radio service for transmitting data in support of diagnostic or therapeutic functions associated with implanted medical devices http://wireless.fcc.gov/services/personal/medicalimplant/.

### 4.5.4 Future development

It is likely that small wearable or implantable medical monitoring devices will become commonplace in the future. Such devices could include technologies that allow the owner to be tracked by a system that can interpret the location of the owner to make assumptions based on their location as to their well being.

Further development of telemonitoring services will profit from the rapid progress in biological sensors, complemented with the always-connected home of the future, to offer home telecare, surveillance and assistance tailored to the needs of the individual. Some examples of personal sensors being actively researched and currently tried out include : Heart rate and blood pressure measurement, ECG measurements for congestive heart failure monitoring, diabetes management through intermittent or even continuous (subcutaneous) blood sugar measurements, cardio respiratory monitoring, oximetry measurements, skin thermography and accelerometers.

The UK DTI sponsored UbiCare Centre at Imperial College, London, is one example of a programme of such research. The aim of the UbiMon project within the Centre is development of a technology platform that can provide continuous management of patients under their natural physiological states such that transient but life-threatening abnormalities can be detected and predicted. The project is initially focused on patients with arrhythmic heart diseases by developing mechanisms to detect and predict abnormalities through long-term trend analysis. In addition, the team will investigate in parallel the use of implantable sensors for post-surgical care, especially in conjunction with minimal access surgery http://www.ubicare.org/projects-ubimon.shtml.

To make the sensors and the associated communication equipment as unobtrusive as possible, suppliers are developing solutions where the sensors are integrated into "normal" items of clothing. The "Life vest" from UK Company Xenetec is just one example of such technology. The Life Vest is able to record heart rhythm, breathing rate and activity http://www.guardian.co.uk/medicine/story/0,11381,1446408,00.html.

## 4.6 User-centred integration of telecare service elements

Apart from the four main types of telecare services which have already been described in this clause, a fifth category of "meta-service" or "brokerage service" should be considered. This conceptual service could be implemented in many different ways, and could be useful to implement an integral and user-centred provision of telecare. Brokerage includes the information and counselling services required to identify, organize and manage support. Brokerage services ideally are delivered independently from the provision of services. They help to ensure that telecare services can be chosen and supervised in ways that respect the preferences, choices and dignity of the individual, as proposed in [46]. Considering brokerage services may apparently add more complexity to existing models, but on the other hand they offer some beneficial aspects:

- adequate user-system interface and communication channels;
- quality and ethics control management for the delivered services;
- integral perception of users' needs by the service providers, taking into account both social and health factors, as well as their preferences;
- optimization of resources; and
- mobility of users.

"There are three main aims about social care services in the future: services have to be user centred, proactive and seamless" [79]. That means putting the person at the centre, thinking about the sorts of things that would help people before being asked and working really closely with other people and agencies, so that there are no barriers between them. At least, two main issues should be considered to achieve this:

1) Existence of an integrated model of telecare provision. The UK Integrated Care Network has published the guide "Integrated Working" [78], where integration is defined as "a single system of service planning and or provision put into place and managed together by partners". This may include mechanisms for planning, commissioning, purchasing, or providing care.

2) Involvement of users: end users should be fully involved in the decisions about their social and health care. On top of the right to express their preferences about the service to be received, it must be considered that most users have some valuable expertise on practical issues concerning service provision. In this context, the Independent Living movement and philosophy should be considered: it is working for self determination, equal opportunities and self respect of older, disabled and vulnerable people [44]. Telecare services may be a useful tool to empower people to take their own decisions. In a work funded by the UK Department of Health [87], several recommendations are provided for the co-ordinated development of comprehensive telecare services to support independent living.

# 5 Deployment drivers, enablers and obstacles

## 5.1 Demographics, policy frameworks and the economic feasibility of telecare services

The EU population is aging; by 2025, 20 % of all Europeans will be older than 65, up from 16 % in 2002 [14]. Across the EU, the number of working age citizens will stagnate or shrink, while the number of retirees will grow [4].

At the time of the 2001 census in the UK, there were 8,1 million people aged over 65 (3,1 million of them living alone). By 2011, the number of people older than 65 is projected to reach just under 12 million and by 2026, over 13 million.

Responding to demands for better healthcare raised by an aging population can increase the cost pressure at a time when health care spending is already on the increase. In 1970, the healthcare-related spending of the OECD countries averaged 5 % of GDP, to increase to 7 % in 1990 and more than 8 % at present. In addition, it exceeds 10 % in Germany, Sweden, Switzerland ant the United States. More than 75 % of all OECD health spending is publicly financed. Based on assessment of countries' experiences, analysis of underlying issues and review of evidence and in order to control the increasing pressure, OECD recommends actions including the introduction of automated health-data systems, strategies making use of new technologies and improved quality of care through better information.

This demographic shift is due to two factors: a reduction in the birth rate and an increase in life expectancy. In 2001, a 65 year old woman could expect to live for another 19 years, compared with only another 12 years for someone the same age in 1965. This increase in life expectancy is mainly due to improvements in health care, which prolong life in people with chronic conditions. However, people living longer often require extended social care services.

Longer life expectancy has implications for the number of dependents per head of working population. Although the rate of dependents will remain fairly constant, the proportion that are older people will increase, and generally these people are more costly in terms of social care provision than dependents aged under 16.

According to the Spanish National White Book on Dependency [30] and based on a European study, the dependency rates have a common profile through the different Welfare State models in Europe. As a whole, severe dependency rates for people older than 80 vary from a minimum of a 26,4 % (Nordic countries) to a maximum of a 37,9 % (continental countries). It must be noted that these figures are based on the self-perception of respondents about their dependency.

This demographic trend means that there will be more dependent people aged over 65, living longer than before and requiring more care and health services. At the same time there will be fewer adults aged under 65 available to pay taxes to fund this care and provide informal care for neighbours and relatives. In addition, people have higher expectations of welfare services than previous generations due to people increasingly seeing themselves as "consumers" in all areas of their lives.

A considerable majority of the dependant population receive informal care, but the population of informal carers is decreasing. Internal population migration in the EU means that an increasing number of adult children live some distance from their older parents.

The tendency for women to have children later in life also contributes to this fall in informal carers. Most informal carers are women, especially in the south of Europe. Women are now becoming more integrated in the labour market: because of that they may not be able to provide informal care activities.

Informal carers are also aging: 20 % of the informal carers are between 65 and 74 years old. The report "The European study of long term care expenditure" [88], published in 2003, compares the situation of long term care in four EU countries: Italy, Spain, Germany and the United Kingdom. This report was financed by the European Commission, and states that "families and other informal carers provide much of the care for dependent older people living at home". The projections made in the study suggest that "a decline in the supply of informal care provided to older people, resulting in increased admissions to residential care could have very considerable financial consequences." This "highlights the importance of services to support informal carers" and also requires "substantial rises in formal services". The report considers that the "development of non-residential services, such as home care and day care, will be especially important". The problem of finding formal carers to look after people in their own homes is also becoming harder. Care provider budgets are tight and the sector is not especially well paid. The work is tough and it is proving difficult to recruit and retain staff.

The problem is how to care for an increasingly ageing population by providing high quality care in a cost effective way. If this problem is not dealt with, the implications are that government spending on health and social services will have to rise, placing an increasing burden on a decreasing number of tax-payers.

Telecare technology can make an important contribution to the provision of high quality, cost effective care for the EU's ageing population. It could be used to extend the period that an older person is able to remain living in their own home and delay the transfer to residential care; as a tool in care needs assessments and as an extra care "reassurance" service for people living in their own homes, whether or not they already receive formal care services. In addition, as older people tend to want to remain independent in their own homes, it increases client satisfaction with the services they receive - something that is difficult to value in financial terms, but is an important consideration for the care provider. Government surveys show that older or otherwise "frail" people want to remain living in their own homes for as long as possible. Given the choice, 80 % want to stay in familiar surroundings rather than move into sheltered accommodation, followed by residential care and finally a nursing home.

West Lothian Council in Scotland have used a trial telecare service, which includes flood and fire sensors since 1999 with some older people in sheltered housing in their area. Over the same period, the average length of stay in residential care has fallen from 3 years to 1,8 years. Part of this fall will may be due to the change in local authority policies for placing people in residential care, but it will also be attributable to the use of telecare to enable independent living for longer.

By helping older people to live independently in their own homes, care providers will be able to free up funds to look after those who need closer supervision or very intensive care. Local authorities in England currently pay a part - or all - of the cost of residential care for more than 163 000 people aged over 65, at an average cost of £15 000 per year. An in-home telecare service might represent very considerable, yearly national savings for local authorities.

Another important driver for the introduction of telecare is the prevention of the delays in discharging older people from acute hospitals and back into the community. When a patient is due to leave hospital, he/she needs to have a discharge plan agreed by both health and social services care staff saying where they should live and what kind of care they will need. This may be a nursing or residential home place, a place in sheltered housing, or returning to their own home, provided it is equipped with the necessary infrastructure and/or personal care support.

Delays in discharging procedures would result in patients remaining in hospital after their treatment is complete because there is nowhere suitable for them to go. This could block the admission of other patients for routine surgery or emergency care, thereby decreasing the quality of service or increasing the cost of healthcare services [107].

Infrastructure developments in Western Europe, particularly the roll out of broadband, are likely to make technology solutions in this domain lower cost and easier to implement. However, some caution must be exercised when considering the whole of the enlarged EU (EU25), where only 47 % of the individuals aged from 16 to 74 years used the Internet (as measured during the first quarter of 2004). More men used the internet than women, and more young people than older, according to Eurostat, the Statistical Office of the European Communities [4].

Another limiting factor to the uptake of telecare services has been a general lack of recognition of the strategic significance of these applications, when used appropriately, to support both quality of service and cost-effectiveness goals of social and health care services. The ageing of the population, reductions in the availability of family carers and cost-containment pressures on public services will all contribute to making telecare one of the ways of delivering services in the future.

All statistics are pointing towards a highly significant demand for technology solutions in this sector. There is a high growth in the retired population, increasing costs in older people care provision, a reduction in non-paid carers and no matching growth in residential care places. Widespread implementation of telecare will impact a large group of professionals including social workers, occupational therapists, nurses etc. as well as care managers, assessors and budget holders.

## 5.2 Clients, carers and coordinators

### 5.2.1 Clients as drivers of telecare services

People's attitude towards technology in general, as well as their expectancy and requirements of health care delivery, has changed substantially during the last few decades. This impacts telecare in the aspects discussed below.

#### 5.2.1.1 A positive attitude towards ICT

People are getting used to accessing various services over the Internet. Using a networked computer for basic health service will therefore be more easily accepted and even welcomed. Internet or mobile phone versions of traditional services are already being implemented, like Web access for setting up appointments, sending prescriptions over e-mail, or receiving appointment reminders on SMS. Wholly new internet-based health services are also being researched and tested out, such as medical examinations over internet, chat rooms for getting medical advice, medical portals for end users, personalized access to individual health data, etc. Many of these projects are receiving EU funding both for development and for deployment. ICT based solutions are being tried out for general communication between doctors, patients and relatives in oncology [20] or for mentally disordered patients [19].

Not all these examples can be classified strictly as telecare, but they give an indication that people appreciate the freedom and flexibility that comes with ICT, as has already happened for banking, accessing public information, and shopping.

#### 5.2.1.2 Population mobility and family infrastructure

The medical profession has long employed trans-national systems for coding of diagnosis and diseases, like SNOMED CT [59], developed by the College of American Pathologists, and the ICD maintained by the WHO [26]. On the other hand people are getting steadily more mobile, and expect to be able to obtain health service independent of their location. This has made it necessary to develop solutions for social security payment that transgress national borders such as the European Health ID Card EHIC [58], and to make their health record available on a national and even pan European level [60].

Clients may prefer to contact their regular doctor at home even when they are away. This would be possible using telemedicine services, such as basic video-conferencing or more sophisticated system for remote diagnostics.

With mobility also comes the breaking up of the traditional family structure. In particular this affects the older people, who often live separated from their children. Investigations have shown [64] that telecare in this case is welcome as a means to reconnect the families virtually, thereby giving close relatives the opportunity to care remotely for the elders, and giving the elders a contact which they otherwise would miss.

#### 5.2.1.3 Efficient usage of resources

As stated already, the aging population and the resulting demographic changes of the western society will stimulate and even force the development and deployment of efficient solutions for health care delivery. Telecare can reduce resource consumption by (at least) the following mechanisms:

- avoiding travel, both for health personnel and the end user;
- making each consultation (virtual or physical) more efficient; and
- targeting the medical expertise to those in real need.

Studies on the cost-effectiveness of telemedicine and of telecare are not unambiguously positive, and some report that the total cost to society of new telecare services equal or even exceed the cost of traditional care delivery [65], [85] and [76]. Most often this is not because the cost of the medical procedures, but rather because of the high cost of new network infrastructure and of new equipment. If in particular the network infrastructure does not have to be accounted for, the cost-effectiveness ratio will be shifted significantly in favour of telecare [66] and [85].

#### 5.2.1.4 Healthcare services to people in remote regions

Telecare can extend the reach of health care to remote locations that would otherwise be without adequate health service. This is most amply demonstrated in scarcely populated areas, like in the north of Scandinavia [67], well known for its pioneering activities within telemedicine, in Australia [83], Canada [80] and the Pacific Islands [97] and [98].

### 5.2.2 Carers as drivers of telecare services

#### 5.2.2.1 Care centres

A care centre needs to control its expenditures, while at the same time delivering its services timely and securely. It may employ telecare solutions for the following purposes:

- efficient utilization of personnel and physical resources;
- allocate and route personnel to avoid traffic delays in cities;
- prioritize home calls according to urgency criteria (based on telecare information); and
- avoid home calls with no-one at home.

#### 5.2.2.2 Professional carers

The professional carer's needs for telemedicine and telecare solutions have been investigated and described in several reports (see e.g. [56] and [90]). The following needs are described:

- to adapt the house call to the current medical situation of the cared person(s);
- to consult written information sources;
- to seek advice from colleagues or experts, giving the remote person access to on-site medical data; and
- to have access to the office computing environment, for consulting the patient record, to report back on the treatment performed, and to receive urgent messages.

Of these, the last three items are telemedicine solutions (on a professional level), and only the first should be considered as telecare. However, a driving force for telemedicine will also be a driving force for telecare, since the network, the software tools and the people involved are mostly the same for both.

#### 5.2.2.3 Informal carers

Telecare solutions can enable a level of presence even when the carer is not physically available (virtual presence). This has been studied amply in several research and prototype projects with future homes [57] and [16]. Telecare solutions can also enable neighbours to take an active part in the supervision and handling of alarms.

## 5.3 Telecommunication technologies and services

During the last 10 years (1995 to 2005), the Western countries have experienced a dramatic development in connectivity to the homes, with regard to speed, availability and standardization. In the beginning of this period, the state of the art was dialled-up ISDN with a data rate of 64 kbit/s, high communication costs, and relatively few households connected. In the UK, less than 5 % of the households had access to Internet in 1995, in 2004, this figure has risen to 52 %. In Norway, 60 % of the households had Internet access in 2004, and the figures are climbing steadily. It can be expected that within a period of ten years, being connected will be as common as having a TV set. At the same time, the connection speed has gone up, so that the norm now is ADSL or even SDSL at speeds exceeding 1 Mbit/s. Perhaps most importantly, being connected over ADSL does not typically carry additional costs other than the subscription fees.

On the software side, Internet Protocol (IP) technology is established as a de facto norm for connecting equipment, and it is now taken for granted that one should be able to connect any piece of equipment to any available network just by plugging in the network cable. New equipment and network installations offer IPv6, with in-built world-wide unique addressing, greatly enhanced security, and different service classes.

During the same period, there has been an even more dramatic development in wireless connectivity. In 1995, GSM offered 9 600 bit/s, and indoor wireless LAN relied on proprietary equipment. Today, UMTS/3G reaches theoretically 2 Mbit/s, with WI-Fi reaching 54 Mbit/s using off-the shelf standard equipment. Setting up a wireless hub at home is plug-and-play, and Wi-Fi is increasingly being deployed in public places like hotels, airports, gas stations, conference sites and the like.

Telecommunication providers, computer makers and mobile phone producers are all now working towards seamless convergence of the different wireless carrier technologies. The major mobile terminal makers are offering or are working on handsets that can connect over Wi-Fi, UMTS and GSM, whereas PDA makers have for some time already offered Wi-Fi and GSM in one package. Access providers work on the integration of mobile and fixed connectivity in the office and in the home.

Together, these technological changes have profoundly changed the way that people communicate and are doing business. Traditional mailed letters are disappearing, being replaced by e-mail, voicemail, and other asynchronous electronic media. "Meeting" each other can now be done via chat, phone, video over 3G, etc. and people expect and demand to be within reach and able to communicate (almost) everywhere.

The progress in telecommunication benefits telecare in several respects:

- ubiquitous IP connectivity eases setup and installation;
- wireless access enables installation without cumbersome and costly recabling;
- home network speed is amply sufficient even for extensive data collection ;
- computer literacy is at an adequate level, especially among the informal carers;
- convergence of cabled and wireless means freedom for the client to move about; and
- IPv6 has security and Quality of Service as inbuilt parts of the protocol, both important elements of a telecare system.

From a human factors view, the development within telecommunications has several implications, both positive and negative, as detailed in table 2.

**Table 2: Impacts of the development of telecommunications on the human factors**

| Development | Positive | Negative |
|---|---|---|
| Lower price | Affordable, larger prospective user group | Unestablished suppliers |
| Smaller terminals | Easier to carry, less intrusive | Cumbersome user interaction |
| Interoperability | Mix and match sensors, communication technology and terminals<br>Pick the best | Difficult choices<br>Possibly inadequate standards |
| Always on | Accessible everywhere | Loss of privacy |
| Large choice of equipment | Flexible, choose best | Must learn lots of new equipment |
| Programmability | Adapt to user, personalization capabilities | Difficult setup |
| Ease of installation | Rapid deployment | |
| Standardization | Possibilities for third-party add-ons | Risk of interference between equipment from different suppliers |
| Internet access | Availability of information and resources | Contamination from network:<br>Virus, spam, etc. |
| Innovative new services appearing all the time | Large selection of services to choose from | Premature market introduction, possibly with bugs and oversights in UI |

Considering human factors can help avoid some of the possible negative consequences enumerated above, and ensure that the end users see technological progress as positive.

In the following are some examples of new services for impaired people that have emerged or have been proposed, based on the latest developments in hardware and communication technologies:

- Using a digital camera to record a scene, process it to detect obstacles, and generate auditive clues that aid a blind person to avoid the obstacles. The idea is not new [91], [92] and today's high-end mobile phones, with camera, stereo audio and ample processing power combine all the necessary hardware in one unit. It seems ideally suited to this task, although to our knowledge, no commercial offerings are yet available.

- Eye-phone, a semi-automatic version of the above, whereby a blind person sends pictures taken with the mobile camera to a remote assistant who explains the scene [17].

- Server-based speech-to-text for the deaf: recording the audio, sending it to a server for processing, and returning the audio as text to be read on the display of the mobile phone. The server-side processing is necessary because reliable speech-to-text is out of reach for current mobile phones.

## 5.4 Equipment, device and solution providers

Makers and vendors of equipment for telecare are facing an immature but fast growing market. There are large opportunities, in particular for SMEs, as for example in the following areas:

- development, manufacture and sale of body sensors that transmit data continuously or intermittently to a surveillance centre;

- integrated systems for surveillance of home dwellers, using information available from sensors mounted in the home (movement, proximity, temperature, etc.) to synthetize a picture of the dweller's well-being, and reporting status either regularly, when deemed necessary, or when enquired; and

- systems for geographically tracking people's location. In a telecare context this can be useful either because the person being tracked is prone to get lost (children, people with dementia), because of a risk of abduction (babies, small children), or because of a need to protect someone else (persons who may constitute a threat to others).

However, the challenges are also many. Body sensors are difficult to manufacture, especially when they are to be worn for an extended period. They are subject to strict medical regulations, and must be put to extensive tests before being marketed for the general public. Integrated surveillance systems are still a research subject, being investigated in several projects for "intelligent" housing, but with no commercial implementation as of this writing. Tracking systems are marketed today, but the ethical problems are largely unsolved, so these systems have so far been deployed mostly for tracking prisoners or dangerous persons, where the ethical concerns are outweighed by the society's need for protection.

To be successful, and to enable the expansion of businesses for telecare equipment, the following items need to be addressed:

- Commonality of medical regulations, so that obtaining authorization for one country makes it easier to get authorization for other countries. The CE mark for medical devices is for a large part fulfilling this need within the EU/EFTA [18]. Unfortunately, the CE mark is not recognized in the United States. Since the CE mark is obtained locally in one country, it is also important to avoid having countries "underselling" each other with respect to medical equipment requirements.

- For successful deployment of telecare services, a high level of data integration is needed: Medical data from patient data records, data from different sensors, services from different companies, etc. SMEs cannot be expected to have the capacity to perform all this integration. It is therefore probable that for large-scale deployment of telecare services to take place, a very active involvement by governmental bodies and R&D institutions will be required.

The current level of standardization for the provisioning of telecare services is neither adequate for easily connecting different types of equipment together, nor for integrating equipment from different suppliers into a common communications infrastructure. Therefore, as a consequence, the highest quality of service currently achievable is likely to be obtained by vertical integration of components from different sources (e.g. sensors, care-phones and monitoring centres).

To open up the market, and to allow for an optimal choice of equipment and supplier, standards for connectivity should therefore be applied. A comprehensive list of applicable standards for health informatics is maintained by the World Health Organization's (WHO) eHealth Standardization Coordination Group [3].

Physical connectivity by itself is not enough, however. One must also ensure a common understanding of terms and nomenclatures, irrespective of differences in sex, age, organization, professional level and nationality between health workers. Only then will it be possible to fully realize the positive potential of a well functioning market for telecare service. In this respect, the work by SNOMED [59] and WHO [26] is particularly significant.

## 5.5 Obstacles

### 5.5.1 Fear and negative attitudes towards technology

Technological scepticism may hinder the acceptance of telecare. This holds true both for persons in need of care and for carers. Especially in this case human factors are very important, and a well designed UI has the potential to be the decisive factor towards acceptance of a telecare solution. Vice-versa, a technologically superb design may be a complete failure from a user's point-of-view. So it is important to consider the human factors and have a user-friendly design from the start.

### 5.5.2 Cultural and religious aspects

In many cultures and religions there is a sceptical or even hostile attitude towards the use of technology. This represents a confrontation with the normally very technologically oriented western culture, but it is nevertheless important that these cultural barriers are understood and respected. To make telecare acceptable also for the technologically hostile, one should strive to make the technological aspects of a telecare service as unobtrusive as possible and putting emphasis on its human aspects.

As an example, the person cared for may be contacted on the telephone by a human carer when something seems to be wrong, as an alternative to being sent an electronic message; feedback from electronic equipment may be sent to a carer instead of directly to the person cared for, etc.

### 5.5.3 Freedom and independence

Technology should be designed and employed to enhance people's liberty and independence. This holds true also for telecare solutions. All too often, however, telecare solutions tie people down and make them dependent instead of independent. People will then be reluctant to employ telecare, and may prefer such solutions to their health problems that do not interfere with their independence.

# 6 Stakeholders' requirements and goals

## 6.1 General

Some requirements on telecare services are generic, irrespective of a client's health condition, age or sex. These aspects are either directly related to human factors, or indirectly through the impact on the user's satisfaction of the equipment. These include aspects of:

- **Privacy:** end users need to have their privacy guarded. Information should not be disclosed unnecessarily to third parties. Whenever private information needs to be disclosed, permission should be requested if possible; otherwise the end user should be informed afterward;
- **Control of information:** every user should be given the means to control which information shall be collected. It shall be easy to find out which information is stored, where it is stored, and to whom it has been made available. If requested, stored information shall be erased, or at least be anonymized (unless storage is required by law). Unless specifically permitted, information should not be kept in storage longer than necessary for the care of the patient;
- **Adaptability:** a system for telecare must be able to adapt to different situations, health conditions etc.;
- Possibility of **handover of responsibilities** (between agents, from agent to informal carer); and
- The maximization of **end user's control**, but with option for remote control of application.

Adopting a "Design for All" approach in the development and deployment of telecare services should always be considered and followed and is of an increasingly high importance. In order to be able to properly understand and address the needs and requirements of all user groups involved, the specific attributes are highlighted below.

## 6.2 Clients

### 6.2.1 Babies

Neonates or babies are, for the purpose of the present document (as well as addressed in other ETSI documents) defined as very young children between 0 to 1 years of age. This category, for the purpose of the present work, includes newborn and premature babies.

Telecare services addressing babies would typically be agreed, set up and managed in agreement with the baby's parents or carers. These telecare services typically consist of monitoring, advisory and paediatric outreach services, provided to rural, peripheral communities, in order to overcome distances and offer the convenience and privacy of a home.

More recently, telecare services have been established to support the delivery of paediatric services and clinical management at remote sites. In the case when large distances separate the clients and centres, a combination of telecare clinics and outreach visits may provide the most efficient means of delivering basic and specialist paediatric care to these clients or centres, as to neonates in Sweden and Australia [10].

A future focus area, mass-produced *intelligent clothing* with Internet and mobile connectivity can improve the health care provided during the very early months of life of many of infants. Intelligent Clothing's wireless technology illustrated in figure 3 and presented in detail in [50] uses low power, low frequency radio and employs and enhances collision avoidance integrity suitable for both the home and hospital environment (up to 25 SmartPatches™ can be used in one room or ward without risk of data collision). Flashing lights in the teddy bear's eyes advise the user that the system is working and, during the recharge cycle, that the battery is fully charged. Data is transmitted to a nearby bedside display unit for onward transmission to a central computer in the hospital or in the home environment.

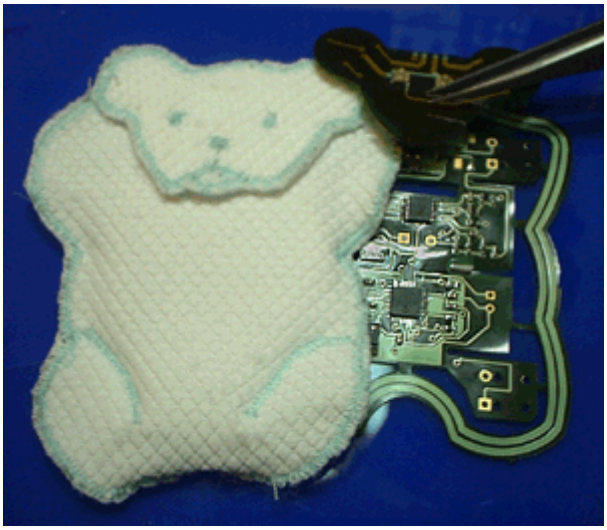


**Figure 3: Example of a baby monitoring device**

### 6.2.2 Children

According to [6] and as for the scope of the present report, a *child* is defined as a person under 12. The ICT literacy of children is comparatively high and continuously increasing. However, it is reported that children are often ignored as a user group when developing ICT devices, services and applications and this applies to most telecare services, too. It is often assumed that childhood is a kind of temporary impairment that will vanish as the body and mind mature, and that special attention to the requirements of children is wasted effort. Furthermore, it is often assumed that children are "Masters of Technology", far superior to adults and have an inexplicable, innate ability to understand the inner workings of ICT and put it to constructive use.

Children are smaller and weaker than adults but increase in height throughout childhood and reach maturity during the age of 16 to 18 [7]. In order to handle equipment designed to be used by adults, children have to find strategies to enable them to reach and manipulate devices such as keyboards, keypads and pointing devices whilst also positioning themselves in such a way as to read a display. Cognitive development progresses through a variety of overlapping stages throughout childhood and includes the sensory motor stage, the pre-operational stage and the concrete operation stage. Child development for the purpose of this work can be, based on [7], summarized as in table 3.

**Table 3: Child development and product design recommendations**

| Development stage; age; category | Development characteristics | Design considerations |
|---|---|---|
| **Pre-conceptual thought; 2 to 3 years (Toddlers)** | - Brief attention span (can only hold one thing in their memory at a time);<br>- Unable to read, but can understand simple instructions; | - Sense organs work as discrete senses;<br>- Attention span is brief;<br>- Manual skills are not fine-tuned;<br>- Present only easy manual tasks;<br>- Feedback should be immediate;<br>- Directions should be verbal. |
| **Intuitive thought; 4 to 7 years (Infants)** | - Understand and can use symbols and words;<br>- Can distinguish reality from fantasy;<br>- In the latter part, can take into account the viewpoint of others. | - Only 50 % of adult size at age 5;<br>- Senses start to integrate;<br>- Strength and physical ability are increasing;<br>- Language skills blossom;<br>- Begin to read. |
| **Concrete operations; 8 to 11 years (Pre-teens)** | - Can classify things;<br>- Understand the notion of reversibility and conservation;<br>- Can think logically (but not abstract yet). | - Senses reach mature functioning;<br>- Sufficient motor skills and hand-eye co-ordination to operate computer functions;<br>- Reading ability means can follow written instructions. |

Children perceive and understand content differently than adults, as the full set of brain functions of an adult brain do not fully develop until the teenage years. As language skills are developing during the entire childhood, children do not have a comprehensive vocabulary as adults.

Children use technology in various locations, for different purposes. The context of use can affect the ease of operation and the safety of use of a product or service.

The aim of [7] is to encourage careful, planned use of ICT products and services by young children, while at the same time encouraging the industry to provide tools and techniques to enable appropriate control of such use. The aim of the guidelines provided is to be technology independent and they refer to existing or near future technologies. Child-specific requirements on telecare services, delivered with the help of ICT, include and influence:

- a safe and secure telecare environment;
- easy-and fun-to-use, accessible devices and services;
- ergonomically correct relationships between system unit, input devices and output display;
- ergonomics of the input devices relative to the strength and co-ordination skills of the child;
- weight and portability of the device and brightness and legibility of the display;
- the operating behaviour related to the safety tolerances of children as opposed to those acceptable for adults;
- the physical design of the system, and whether it is suitable for the environment that it is likely to be used in;
- the portability of the devices, including the facility for it to be considered as wearable;
- the power supply, including batteries and feedback about their status being in a form that can be comprehended by a child; and
- the use of text and other representational metaphors to assist the child to operate the system, particularly as abstract metaphors may not be comprehensible to a child.

### 6.2.3 Older, impaired and disabled users

Adopting a "Design for All" approach in the development and deployment of ICT products and services in general (and specifically, telecare services for the scope of the present document) should always be considered and is of an increasingly high importance.

"Design for All" does not automatically imply that all products and services can be made usable by every user. This would be impracticable, if not impossible [5].

In addition, it is acknowledged that there will always be users who, because of severe impairments, need specific specialist equipment or additional assistive support to use mainstream technology [1].

As proposed in [5], a three-layer approach model can be applied to the development and deployment of telecare services:

- **mainstream products** should be specified, designed and deployed according to good usability and human factors practice, incorporating considerations for people with impairments, that can be used by a broad range of users;
- **products that are adaptable** to permit the connection of assistive technology devices (outside the scope of the present document);
- **specially designed or tailored products** for users with multiple or very severe disabilities (outside the scope of the present document);

In order to be able to properly understand and address the needs and requirements of all groups, the specific attributes need to be highlighted. This is the scope of the following clauses.

#### 6.2.3.1 Physical impairments

Physical impairments, as described in detail in [5] with an impact on the use of ICT include impairments relating to the production of speech, dexterity, mobility, strength and endurance.

**Speech** is the most important sound produced by the voice. Hearing impairments may indirectly affect speech, due to changes in the perceived feedback. Telecare service clients with severe speech defects (often linked with deafness) may use text-based communication, if they can read and write. The use of synthetic text-to-speech generation is typically recommended. In addition, the unforeseen success of 3G video calls can provide support for lip reading or manual (one-handed) sign language, although this facility is sometimes not useful to those who lack control of lip movement. In addition, it may open up the possibility to users who otherwise have considerable difficulties to use telephones, due to their limited abilities to produce eligible speech, more easily contact emergency assistance services.

**Dexterity** is defined as the skill of manipulation and implies co-ordinated use of hand and arm to pick up and handle objects, manipulating and releasing them using the fingers and thumb of one hand (it can also mean right-handedness). Dexterity impairments include the inability to bring fingers and thumb together or the inability to separate them normally. More complex operations, such as simultaneous push and turn may be painful or even impossible. The necessity for rapid motor activity during the performance of tasks shoals be avoided.

**Mobility** is the ability to move freely between places and locations. Mobility problems can extend from minor difficulties in movement, to the need of using a wheelchair or being bed-ridden. Telecare clients with impaired mobility may also have extra, involuntary, uncontrolled and purposeless movements. They may also have small or missing limbs and face difficulties to access interaction elements of telecare services. People with a poor control of their movements (e.g. cerebral palsied) may not be able to keep the look fixed on the screen, with the risk to loose part of dynamic information.

**Strength and endurance** relate to the force generated by muscle contraction and can be the force exerted with a specific part of the body on a specific object. It also depends on endurance or stamina (the capacity to sustain such a force) and can be related to heart and lung function. The provision of speech control (e.g. [2]) and hands-free facilities is often considered beneficial.

#### 6.2.3.2 Sensory impairments

Sensory impairments with a high telecare relevance include impairments related to sight and hearing. Impairments with a lower ICT significance relating to touch, taste, smell and balance are not addressed in the present document.

**Sight (or vision)** refers to the ability to sense the presence of light and to sense the form, size, shape and colour of visual stimuli. There are various visual impairments that can lead to a disability when using telecare services and include myopia (short sightedness), hypermetropia (long-sightedness) and astigmatism. These can normally be corrected with suitable lenses. However, even if the vision of a client is corrected, there can still be difficulties with small character sizes, poor contrast and improperly selected fonts. Typically, the simpler the image and the clearer its definition, the easier it is to read.

7 % of all males (but less than 0,5 % of females) have difficulties in distinguishing red from green, an effect known as **protanopia and deuteranopia**. Colours should therefore not be used stand-alone to indicate vital status or functions. Additional modes of information should be provided redundantly. Colours should be chosen so that they are easy to separate into distinct grey-tones when transformed into the monochrome grey scale.

The most severe form of visual disability is **blindness** (classified in terms of perception of light) or loss of central vision. Some telecare service users will not perceive light at all, some can distinguish between brightness and darkness, and some can perceive slight movement or some images. Loss of sight can involve one eye, leading to a loss of depth perception, or both eyes. When vision is reduced to 10 % of normal vision or less in the best eye, a person is generally considered "legally blind" in most countries.

Telecare service users with visual impairments may:

- face difficulties to locate or identify telecare equipment elements;
- not be able to perceive a visual output (texts, images, symbols, etc.);
- face difficulties to understand complex graphics or fonts;
- have difficulties to perceive visual messages with a low contrast with the background;

- be sensitive to glare and reflection; and
- loose details from information in poorly illuminated scenarios.

**Hearing impairments** are typically divided into three categories, depending on the degree of user's hearing loss:

- moderately hard of hearing people with an average hearing loss (AHL) of 50 dB to 60 dB;
- severely hard of hearing people with an AHL between 70 dB to 92 dB;
- profoundly deaf people with an AHL greater than 92 dB.

Telecare service users moderately hard of hearing may have difficulties in hearing warning tones (e.g. alarms sounds), call progress tones and other auditory indicators. They benefit from multimodal presentation of the signals provided by, for example, flashing lights or vibration capabilities.

Severely hard of hearing generally use hearing aids. It is beneficial to provide inductive coupling facilities for such hearing aid users.

Hearing loss can basically be classified into conductive and sensory-neural loss. **Conductive loss** occurs when some defect, infection or damage to the outer or middle ear makes the ear less efficient in transmitting vibrations to the inner ear (often treatable and can be helped by a hearing aid).

People born deaf (or who have lost their hearing before they learnt to speak) are called **pre-lingually deaf**. These people will typically have no speech or poor speech intelligibility and poor or no reading abilities. People, who lose their hearing later in life, after they have acquired at least one spoken language, are called adventitiously or **post-lingually deaf.** Depending on the time of onset of deafness, these people may retain anything from intact and fully intelligible speech to very unintelligible or no speech at all. The reading abilities of post-lingually deaf people are normally also retained, but some post-lingually deaf users may not be able to read or not read very well.

Deaf people who cannot hear over a telephone, but have a reading ability, require text communication options, preferably both fixed and mobile solutions. Text telephones and relay services (preferably operational on both fixed and mobile networks and without network-related restrictions) are necessary to enable them to communicate with telephone users without that facility [8].

#### 6.2.3.3 Cognitive impairments

Cognitive impairments with a considerable impact on the design and use of ICT include impairments related to the intellect, memory and language and literacy.

**Intellect** is the capacity to know, understand and reason. As people get older, they keep their basic intellectual abilities (unless affected by illness such as dementia) but concentrating and paying attention to a task becomes more difficult. In addition, as people get older, they require more time to perform most tasks and memory capacity available for the storage of new information decreases.

**Language and literacy** are the specific mental functions of recognizing and using signs, symbols and other components of language. Dyslexia is often considered an impairment of language, although it may be classed as a defect of vision. Mild forms of dyslexia are very common but can easily be overcome by simple, short and accurate instructions in a combination with illustrations and other graphics.

Telecare service users with cognitive impairments and disabilities may:

- easily forget where they are in a sequence of actions or operations;
- face difficulties to remember codes which might be necessary to use a telecare device, or to remember which control to use to start/stop a telecare device;
- have difficulties to remember sequence elements or tasks, and thus may not be able to follow complex procedures with many steps;
- take a longer time to react when the telecare service is demanding an input, as they can not remember information quickly and may find it difficult to choose among a set of options;
- get confused when waiting a response from the system, and not obtaining it immediately;

- not be able to find the cause of a telecare service malfunction, and may have difficulties to find the solution for a detected problem;
- feel disoriented in a speech UI;
- face severe difficulties to contact emergency services;
- not be able to process information only provided in acoustic form; also if the information is too complex, be it written or spoken; and
- get confused with complex visual configurations.

#### 6.2.3.4 Other impairments

Other impairments may include disabilities such as allergies or cultural aspects, not addressed by the present document.

#### 6.2.3.5 Effects of aging

Aging per se should not be considered as a certain state that requires dedicated telecare services. The effects of aging (in a health care perspective) can therefore be treated with respect to the impairments related to aging, such as reduced sight and hearing, impaired motor skills, dementia and less precise control of body functions.

However, there is one effect which is particularly related to aging, namely the gradual loss of friends and relatives of similar age, and the ensuing loss of a person's social network. There is therefore a special need for telecare services to extend the social sphere of older people, both geographically so that distant friends and relatives can be included, and across ages.

The proportion of the population older than 60 is expected to increase considerably and as a result of prolonged life expectancies, the percentage of the very old (clients aged 80 years and older) is expected to increase substantially. Many of these potential telecare clients will have strong preferences towards a normal life at home, for as long as possible, instead of hospitalization or living in service centres.

Older people clients experience a change or degradation of human characteristic [5]. In general, most functional abilities will degrade. For example, older people tend to lose their ability to detect higher frequency sounds and many use a hearing aid. The incidence and severity of visual impairment increases with age and the changes in the physical structure of the eye will lead, among other effects, to loss of visual acuity (the ability to see fine detail), the inability to accommodate changes of focus from short to long distances and a loss of speed of adaptation to changing light levels. Manual dexterity, mobility, strength and endurance decline. These effects are often accompanied by a slowing of the brain's ability to process information, causing difficulty in taking in, attending to and discriminating sensory information. This has the effect of causing an overall slowing of "behaviour" and the phenomenon which is generally referred to as "loss of memory".

CEN/CENELEC Guide 6 [25] provides further information on the affect of ageing on human abilities. It should be noted that the "normal" changes related to ageing are usually not regarded as disabilities, even though the impairments incurred by ageing may be indistinguishable from those of younger disabled people.

Human factors of telecare services dedicated to the older people should take into account the abilities and impairments of older people and aging clients.

### 6.2.4 Clients with chronic needs

The World Health Organization has identified that chronic conditions will be the leading cause of disability by 2020 (http://www.who.int/chp/about/integrated_cd/en/). However, many models of healthcare provision in the world do not focus sufficiently on managing these chronic conditions. There is a new drive to detect illness more proactively in the community, and to intervene in cost-effective ways that improve quality of life for the individuals concerned. Linked to the move towards improved chronic disease management are initiatives that promote self-care by clients. In the UK the Expert Patient initiative aims to empower patients to take more control of their lives and healthcare, and to work in partnership with health professionals in order to achieve optimal health status. All of the UK National Service Frameworks emphasize the importance of self-care in managing long-term disease [77].

For patients to take control of their own condition, they need good information services, at the right time and in the right form. This includes well-validated references for further information. Advice and support on how to use the information is crucial if patients are to be able to make fully informed decisions about their own care. Telecare solutions for people with chronic disease should provide the following benefits to the client:

- establishment of improved relationship between clients and carers, be that clinicians, family or others;
- proactive personal involvement in treatment, power and choice to actively manage medical conditions;
- ability to detect adverse trends in health proactively and respond before significant damage is done;
- improve the management of their disease leading to better outcomes, improved quality of lives and an increase in the standard of services;
- ability to share information with the clinicians/experts who support their care, making face-to-face time with them more productive and effective;
- feedback to drive up motivation and bring about behavioural change required for effective self-care; and
- increased productivity and less cost of care in the home environment; parents, family, friends.

### 6.2.5 Other clients

Clients not comprised in the previous categories (children, older people, impaired and disabled and chronically ill clients) are people who may temporarily need supervision or healthcare services at home or on the move. This may be due to an accident, with a period of trauma care at home, e.g. wound healing. It may be due to an acute illness which requires supervision during a period of reconstitution, e.g. mild heart congestive failure, or sudden, unexpected epileptic attacks. It may be a health condition which requires measurements in normal environment, e.g. so-called "white-collar hypertension" (hypertension caused by just being in a doctor's office).

For the above clients the period of use of the service may be comparatively short, and the client may not have been in much contact with the health care system previously. He or she may therefore not be accustomed to routines and procedures which the health care workers take for granted, and may even be hostile to the thought of being in need of care. People in this group also may be particularly resentful to wearing devices that betray their condition to the environment. Telecare devices and services for this group should take this into account, and in particular be designed with the following priorities in mind:

- non-obtrusiveness, if necessary at the expense of durability (small and expendable devices rather than bulky and sturdy); and
- ease of use and rapid learning at the expense of functionality and user choices ("one size fits all").

An additional group of temporary clients are pregnant women, who for some reason need supervision during part of the pregnancy. Their priorities and needs are somewhat opposite to the previous group, since coming mothers normally have no need to divulge their need of healthcare, they are also highly motivated to learn and use the services offered. It may therefore not be a requirement that the service be non-obtrusive, and if necessary, a training period is acceptable.

## 6.3 Carers

### 6.3.1 Professional carers

Professional carers are those health and social care workers that come into direct contact with the client. As a profession they are medically educated and trained, and they are used to continual re-education whenever new equipment and new procedures are introduced.

Typical problems for the professional carers are:

- little time for each client, frequent rescheduling due to staff changes;
- too much time on reporting, scheduling, planning and general office work;
- home visits inefficient due to traffic, long driving distances, etc.;

- professional isolation when working outside of the institution;
- inadequate equipment when outside of the institution; and
- lack of client-specific information.

Telecare services targeted for professional carers should solve one or more of these problems. However, the professional carers are a conservative group, very concerned about the safety and security of the clients, and new procedures are only accepted when the usefulness has been proved and the safety can be guaranteed. To be accepted by the professional carers, a telecare services must not lead to a degradation of the service given to the client, or otherwise work at the expense of the client's interests.

### 6.3.2 Informal carers

The practice of caring for older parents within the family setting is declining, partly due to female carer pattern changes and the trend to start families later in life. House price increases and increased mobility in the population over recent decades also mean that it is less practical for families to accommodate older people parents into their homes. Distant adult children of older parents are likely to be early adopters of basic monitoring services where general activity patterns are detected and relayed for "peace of mind". Such a service has been available in Japan since 2002 [105].

The market segment involving informal carers is likely to have at least two forms of service model. The first may be a low cost entry level solution for families to purchase and self install sensors in the home of the older person. Once installed, the sensors may be registered with a communications portal and the distant family members identified as the recipient of alerts and alarms. Whenever a situation occurs that may be a cause for concern, a nominated family member will be notified and will take responsibility to deal with the situation. Such systems are likely to be relatively inexpensive with a low subscription fee to the portal provider.

A second, more comprehensive response service might also be offered to this market segment, whereby a third party service provider local to the older person undertakes to provide a response to some or all types of alerts. Families will most likely want to be able to move seamlessly up the functional ladder between the basic system and the formal response service without having to replace the hardware in the home. UIs must be designed to be intuitive and accessible to all types of carer - old and young. Privacy of data and analyses must be preserved. There must be some process by which the client is involved in allowing access to data by third parties who may be nominated by carers, for example during periods of respite care.

## 6.4 Coordination agents

With reference to figure 1, coordination agents are individuals who perform the role of operator in the model as described in clause 4.1. Typically a monitored home would generate data or alarm instances which may be transmitted to a call-centre in order to monitor the client's status. The status monitoring function may be undertaken by an automated process in a computer system within the call-centre, with only anomalous behaviour or trends flagged to a human operator. The operator role is usually one of coordination. It is the operator who will make a judgement about if and when to involve a third party such as a clinician, a community carer, a family member or the emergency services. In some situations, depending on the degree of intelligence and autonomy within the home installation and the configuration of the service, the coordination role is not required and is subsumed into the functionality of the client's home system, in which case calls to third parties for assistance are made directly between the home and the clinician, carer or emergency services.

There are, however, many existing services in which the coordinators are real people performing a judgement-based role within a call-centre. The majority of dispersed panic alarm services already work in this way. In this case the coordinator has to open a voice channel to the client, hold a dialogue and make judgement about how to proceed. In many cases there will be written protocols to support the judgement of the coordinator. A more recent model, particularly in the US, is the role of clinical coordinator. In this situation the call-centre system might be receiving physiology data, such as blood sugar levels. The physiology data can be received and entered automatically to an electronic patient record, however, if that data is deemed to be outside predetermined limits the coordinator's attention will be drawn to the record and it will be their role to coordinate a response. In this situation the response might be to call the client and discuss diet or therapeutic issues, alternatively they may facilitate the link between the client and an expert clinician.

For the coordination agent to be as effective as possible attention must be paid to the human factors issues associated with their working environment. Clearly many of these will be covered by standard call-centre, or office based, guidelines such as [96]. However, for effective coordination the telecare service has to be designed to meet the needs of the operator. This will include careful layout of data screens, ensuring that all the appropriate information is available to the operator when they need it, it will include appropriate methods for the capture of input by the operator. Operator input may include changes to parameters on remotely controllable devices in the home, or the onward connection of data to third parties. Whatever coordination activities are undertaken, including a voice dialogue with the client, an appropriately secure record of such actions must be kept for service audit purposes. Resources must be specifically allocated for training of coordinators, as they may be the client's primary link to assistance and as such they should be equipped to deal with such situations.

## 6.5 Healthcare providers

The EU eHealth agenda is driving a change in health care delivery away from the traditional structures of large centralized hospital facilities towards decentralized care provision by community based health and social care providers. There is an increasing emphasis on maintaining the well-being of clients through proactive chronic disease management, health education and self care programmes.

A move towards "community" focused care, where health and social care is provided within the client's own home or local environment can enable:

- a shift to fully supported self-managed disease prevention;
- shorter hospital stays, releasing hospital resources earlier;
- individuals to recuperate within the comfort of their own homes;
- clients with chronic conditions more independent living; and
- older people to remain independent in their own homes longer.

As an example the UK National Health Service (NHS) is moving to a more preventative approach in all of its work and has published National Service Frameworks (NSFs) for a range of chronic conditions, including diabetes, coronary heart disease and renal disease. These set out national standards of care to be delivered and targets to be met on treatment of those conditions. The UK National Programme for IT (NPfIT) sets out various targets for NHS delivery of services, including:

- January 2006 - December 2007 - "home telemonitoring" available in 20 % of UK homes requiring it; and
- January 2008 - December 2010 - "home telemonitoring" is to be available in 100 % of homes requiring it.

The new contract for GPs in England requires production of evidence that the care they provide is effective. This includes meeting targets set for the care of patients with particular chronic conditions, such as diabetes. As an example one of the targets is to lower Hba1c levels, which give an indication of control of blood glucose levels, monitoring is an essential part of controlling blood glucose levels. GPs will therefore be given incentives to find techniques by which their patient populations can have their health status managed more effectively http://www.dh.gov.uk/PolicyAndGuidance/HumanResourcesAndTraining/ModernisingPay/GPContracts/fs/en.

In England, this approach has been endorsed by the NHS National Improvement Plan issued in 2004 [103].

A key enabling technology to support this distributed model of care delivery is the national electronic patient record. By 2010. The NHS Care Records Service will provide all NHS patients with an individual electronic NHS Care Record, which will detail key treatments and care within either the health service or social care. The NHS Care Records Service will connect more than 30 000 GPs and 270 acute, community and mental health NHS trusts in a single, secure national system. In order to support client mobility across the EU, interoperability and coding standards need to be harmonized between national care record systems. In order to achieve such harmonization cultural differences between health and social care providers within countries will have to be addressed in addition to cross border differences. These issues are addressed by the CEN/ISSS *e*-Health Standardization Focus Group [60].

Healthcare providers must be able to design new service delivery models around ICT systems that are robust and reliable, with well defined operating parameters. A care service provider should be able to accept data from any appropriate end user terminal device irrespective of manufacturer, for example a specialist diabetes support service should be able to accept data from any communications-enabled gluco-meter available in the market. In doing so the provider needs to be assured of the quality of the data with respect to device calibration, data security and data integrity. For such a scenario to be viable devices need to work to open published standards.

## 6.6 Social care providers

In the UK personal social services are usually the responsibility of the Local Authority social services departments, this includes help with meals, dressing and bathing, as well as respite and residential home care. These services are provided either by the local authority themselves, or by a private agency contracted to the local authority. Recipients may make a contribution towards their care, depending on their income level. Based on UK Department of Health Care Statistics for 2001-2 care for the older people was £6,4 billion. Cases that require residential care cost five times that of domiciliary care and there is significant pressure to develop technology and systems to support people living at home for as long as possible. This impacts a relatively large group of professionals including social workers, occupational therapists, nurses etc. as well as care managers, assessors and budget holders. Each has their own perspective on telecare and the consequential requirements from the service.

Using telecare to delay the move into residential care is attractive to Local Authorities as it reduces the problem caused by the lack of availability of residential care places, as well as providing care at a lower cost. Also, as older people tend to want to remain independent in their own homes, it increases client satisfaction with the services they receive - something which is difficult to value in financial terms, but is an important consideration for the Local Authority.

Telecare solutions for social care providers will be focused on risk management systems that reduce the risks associated with an individual living in the community, usually on their own. Typical systems monitor aspects of home security and safety such as inadvertently unlocked doors and windows, or gas appliances left on. Social telecare services also monitor behaviour patterns of the individual user and seek to raise alerts and/or alarms when an individual appears to be incapacitated. As such systems become widespread social care service providers will need to operate across various vendors systems. Such systems may have been installed by the individual user or their family prior to the user becoming a formal care service client. Additional service provision costs would be minimized if care providers were able to assess the functional ability of any pre-fitted telecare service and then adopt, or enhance and adopt, the existing hardware into their service package. For this to be a reality the social care system suppliers must work to published open standards and protocols. System specificity and sensitivity must be published and calibration tests designed to ensure continued safe operation as service provision moves from one supplier to another.

## 6.7 Third party suppliers and the voluntary sector

The private sector could play an important role in the early adoption of telecare and the delivery of telecare services. As private sector care providers already deliver many care services, it is likely that they may provide telecare services under contract to Local Authorities or other government agencies. For these organizations, telecare might provide a way to differentiate their care offerings as well as increasing their customer base beyond their own care homes or dedicated housing.

Interoperability of in-home hardware from various suppliers will be required if care providing agencies are to be able to compete and differentiate themselves at a service level.

## 6.8 Housing and infrastructure providers

In many countries, government housing departments have a responsibility to provide sheltered accommodation to those citizens deemed to be in need of support. The cost of housing stock and the demographic bulge in older citizens means that governments may be unable to meet their commitment in the future. They are faced with two choices: raise the acceptability criteria for clients or find alternative means of supporting individuals in their own homes/local communities. Telecare services offer an alternative whereby clients can be supported for longer in their own home, thus reducing the total lifetime spent by that individual in the sheltered or residential housing stock. Housing departments have a critical role to play in telecare provision as they are usually the providers of any assistive technology into people's homes. In the UK telecare hardware is already defined as a class of assistive technology and therefore housing departments need to work in partnership with the health and social care providing agencies with respect to planning, installation and maintenance of telecare services.

Physically adapting houses and dwellings for handicapped can be costly (wheelchair adaptation, one-storey reallocation of rooms, etc.), and is therefore not done up front. However, the basic infrastructure for telecare consists mainly of cabling for data transmission, together with a sufficient number of power outlets. If tubes and/or pipes are laid in advance when the house is built, the actual drawing of wires can be postponed until necessary, and the cost for infrastructure will not be significant. Wireless solutions can be used when fixed wiring is impractical, however, fixed wiring is better for safety, security and speed. As a consequence, construction companies should be given incentives to lay out an adequate network of tubes/pipes in preparation of house mounted telecare equipment.

## 6.9 Access and telecommunication providers

Telecommunication network access providers ("telcos") used to have a strong foothold in the medical sector. They are now, however, facing fierce competition in a rapidly changing market. The competition takes place on several levels:

- On the basic communication level, deregulation has enabled new players to offer high bandwidth access in direct competition with telcos. The most important ones are:
  - TV cable companies, offering internet access on the TV cable;
  - electricity suppliers, who can profit from their installed grid of high- and medium-voltage supply as support for long-distance fibre based communication network. Some also distribute internet to the households;
  - railway companies, who already have an extensive communication infrastructure along the tracks;
  - large corporations who can lease out parts of their private network.

  The health sector profits from this, seeking the cheapest supplier, often without regard for network availability and quality of service.
- On a basic service level, new technologies (3G, Wi-Fi, VoIP etc.) is eroding the traditional Plain Old Telephony System (POTS) both as a technical platform and as a source of revenue. Small upshot companies with few employees and relatively little capital outlays can drive prices down, and take over a significant proportion of the standard telephony market. This occurs for instance by offering IP telephony at a fraction of the fixed telephone costs, with possibilities for a large spectrum of new and useful services. Since (standard) telephony is not a life-critical part of diagnostic or treatment, the health sector is following this trend, eager to save on communication costs. As an example, the completely rebuilt St. Olav's hospital in Trondheim (Norway) will be based exclusively on IP telephony, when finished (in 2007).
- On the service integration level, the position of the telco as an integrator and provider of middleware is equally under attack. Services which were formerly intrinsic to the communications infrastructure, can now be supplied by external middleware. Examples are voice recognition, hand-over mechanisms between telephone and internet communication, etc.

On a short term basis, the network and infrastructure providers may react by fencing the customer in, making it difficult or impossible to integrate services from other vendors. However, on the long term this is a strategy that the health sector will not tolerate (compare with the evolution of the DICOM standard for exchange of digital X-ray images [101] and its influence on the radiology equipment business). It is therefore in the interest of the network providers to open up and standardize the health networks as much as possible. This is all the more important because of the very stringent security requirements of the health sector (in terms of safety, availability and confidentiality). Only when interfaces and system specifications are open is it possible to validate that the level of security is acceptable.

Many telcos now position themselves as a high-level support industry for the health sector. Most of the major European telcos have R&D programs devoted to health, and are finding niche markets where they can exploit their competence and expertise within communication to catch a portion of the increasing health budget allocated to ICT. For instance the telcos offer services and products within secure communication, for routing and amalgamation of data from diverse sources, and for safe long-term storage of data.

The underlying network infrastructure is migrating to the new IP v6, with greatly enhanced functionality compared to IPv4. If IPv6 can be extended all the way to the customer's installation, this enhanced functionality can result in new services and better network quality. This may enable most or maybe all services to use the same IT infrastructure, including data-capture, data storage, security, billing, analysis, and feedback and support functionalities. Telcos see such services as a means of driving up value added services across their networks and therefore generating new business opportunities.

The mobile telephone is taking over market segments which formerly used exclusively wired telephone. This is now happening in the hospitals, where the ban on GSM is gradually being lifted, and wireless DECT handsets are being replaced with mobile phones. The telcos offer almost endless possibilities for call blocking, billing according to destination, base station and time-of-day, roaming and handover, positioning etc., possibilities which are just starting to be exploited. It is also significant that most scientific evidence seems to point out that the radiation from GSM handsets are not harmful to humans as long as they are kept below levels set forth by the International Commission on Non-Ionizing Radiation Protection, ICNIRP [102].

## 6.10 Equipment vendors

### 6.10.1 Electronic assistive technologies (EAT)

As described in [15], the AT industry is characterized by a large number of small companies marketing a limited range of devices which may be for a specific disability or for a specific application area. They usually have to face situations where prices tend to be high, compared with mainstream products, and profit margins are modest. This is the reason why few companies can devote significant resources to research and development.

Among the goals and requirements of existing organizations of AT developers and vendors, several could be outlined:

- improvement of the AT awareness and advice support among population;
- enhancement of the public financial support to AT consumers, which helps to create more stable markets;
- creation and further development of open interaction activities with consumers of AT, service providers and advocacy organizations (e.g. ATIA Annual Conference: http://www.atia.org);
- market research to discover untapped markets: e.g. companies' efforts to retain valuable professionals who develop disabilities because of aging, stroke, illness, etc.; companies wishing to recruit talented people regardless of their physical or sensorial abilities [71];
- increase of interoperability among technical aids from different manufacturers or different functionalities, and also of that between technical aids and general purpose ICT equipment;
- enhancement of AT Involvement in those Information Society policies regarding Accessibility: e.g. Accessibility Requirements for Public Procurement in the ICT domain;
- improvement of AT companies' administrative practices: suitable business plans and planning processes and commitment to ethical standards; see [41];
- reinforcement of AT companies' collaborative relationships with local, national or international organizations and institutions (administration, universities, etc.);
- development of the commitment with consumer needs;

The report [15] summarized the point of view of people concerned with assistive technologies;

- standards are useful but they must allow for future developments;
- a standard is of limited use if it is not widely implemented;
- many disabled users of assistive technology have limited technical skills, so the setup and operation need to be simple and consistent;
- the technical interfaces should not increase significantly the cost of the assistive devices;
- any standard should build on the work already done by Excellence Centres working on AT; and
- develop and improve further the interaction between manufacturers, users of EAT, service providers and advocacy organizations (e.g. ATIA Annual Conference: http://www.atia.org).

### 6.10.2 Home safety and security monitoring

Local authorities and private organizations within the UK have used community alarm systems for many years. Over a million older and disabled people in the UK use a community alarm service with most of them having their calls answered by a call centre, sometimes called a "care-line". There are over 300 community alarm service providers within the UK, the majority of which are local authority housing departments. It is estimated that around 60 % of these service providers use solutions manufactured by Tunstall. There is a move within this industry towards incorporating more sophisticated passive sensors such as flood detectors, fall detectors and movement sensors.

Most manufacturers of community alarm systems in the UK are members of the Association of Social Alarms Providers, ASAP, the UK trade association representing the interests of the social alarms and telecare sector. A comparison of the systems manufactured by ASAP members can be found on the Research and Information for Consumers with Disabilities (RICA) website: http://www.ricability.org.uk/reports/report-telecoms/Community%20alarms/contents.htm

**ASAP Code of Practice:** the accepted standard for the professional management of social alarms services (endorsed by the DTLR/ODPM as the applicable technical standard within the Supporting People guidance). Attainment of the standards within the Code of Practice is determined by ASAP following an independent audit of the service. There are three parts to the Code of Practice (1 Calls Handling Operations, 2 Dispersed Alarms Operations, 3) Response Service Operations). ASAP is developing a new web site to cover telecare. More information is available at the ASAP web site at www.asap-uk.org.

**ASAP Good Practice Guides:** Planning, design and construction; Business continuity planning; Management of performance; Managing access; Management of computer systems are now available for service providers.

Also: **National Initiative for Telehealth (NIFTE) Framework of Guidelines** is the result of a national, multi-stakeholder, interdisciplinary collaboration and consists of a structured set of statements designed to assist individuals and organizations with the development of telehealth policy, procedures, guidelines, and/or standards. Based in Canada: http://www.cst-sct.org/.

### 6.10.3 Information provisioning

The user groups who most likely will have special requirements relating to ICT accessibility include people with impairments, older people and children.

In accordance with Article 7 of the Universal Service Directive, EU Member States shall take specific measures to ensure equal access to and affordability of publicly available telephone services for disabled users. This is also applicable to the provision of telecare services offered through the telephone.

In addition, with the development of the information society and users' developing familiarity with and trust in public and private Web sites, the latter are quickly becoming the most available access portals to information, education, culture and the consumption of products and services at schools, businesses and in homes.

Accessibility issues are of paramount importance for information provisioning to the above mentioned user groups. ETSI has addressed related generic aspects in [5], [6], [7] and [9]. Although not telecare-specific, these are applicable to the human factors of telecare.

In addition, and due to its nature, telecare equipment and the related functionalities provided should be easy to explain to users. The equipment should also be designed and deployed in a way allowing for easy, efficient and reliable use and maintenance without difficulties in its setup, configuration and operation, including the equipment and enabled services.

Last but not least, as mentioned in the previous clause, the ASAP Code of Practice in the UK covers telecare services and provides Good Practice Guides to various related aspects by making them available on the Web - a recommended practice. It can be hoped that the Web Accessibility Guidelines, WAI [12] are applied.

### 6.10.4 Personal monitoring systems

There are at least 80 commercial suppliers of home telemonitoring systems or supporting devices in the world, many based in North America. Solutions include both wired and wireless solutions for capture of all the common vital signs such as ECG, BP, weight, pulse, blood oxygen saturation, spirometry, blood glucose etc. These systems have been developed to use a variety of network access technologies including PSTN, ISDN, IP, etc.

In many cases the measurement devices upload data into a patient record. The patient record can be held locally in the home, or on a network server. Conditional access to the patient record can be granted by the patient to third parties such as GPs. Often the technology used to create the patient records or the data transport protocols are proprietary and therefore do not lend themselves to easy transfer from one product/supplier to another if a client wishes to change.

## 6.11 Conflicting goals

From the analysis and description given above in this clause, it can be inferred that many of the goals for telecare services and are conflicting, and cannot be realized all at the same time.

- Standards versus proprietary solutions: Equipment suppliers, communication providers, and even health care workers may want to tie the end user into their particular service or equipment, whereas the end user wants the freedom to choose the best service.
- Generality versus specialization: From a supplier's viewpoint, a general, extensible system which can be tailored to many different users is preferable. From a user viewpoint, it may be better with a system or service tailored to his/her particular needs.
- Open versus secure systems: There will always be a conflict between the need to have easy access to data and the need for privacy and security.
- Conflicting technical requirements: Weight versus robustness; flexibility of wireless operation versus speed and security of wired operation; small size versus functionality, etc.
- Conflicting requirements of the UI, in particular expert versus novice usage.

It is typically and ultimately up to the supplier of the telecare service to find the best compromise between these conflicting goals.

# 7 Human factors and the usability of telecare services

## 7.1 Usability, accessibility and UI issues

Due to the complexity of telecare services and the numerous solution elements involved in the design, delivery, setup, configuration, use and maintenance of telecare services, the human factors and usability of telecare services must cover such aspects as the ergonomics of physical devices, compatibility and complexity of equipment and services, UI aspects, set-up and configuration , user education and training, price and cost transparency aspects, communication terminals, network access and applications.

One of the most important goal of human factors, usability and accessibility activities in telecare is anticipate use cases and provide design solutions to eliminate errors that could cause harm to the client or to the carer. In order to be able to achieve this goal under the various constraints and user requirements described in clause 6, user centred design and development approaches play a very important role. Telecare services should not be technology driven but user centric.

Furthermore, there are two directly applicable medical device usability documents, an EN ISO standard and an IEC Committee draft [108] to [109].

In the below, in addition to [1] to [2], [5] to [9], [12], [13], [25], [27] to [28] and [89], a non-exhaustive list of the more important key characteristics of the usability, accessibility and UI-related elements of telecare services are presented (in alphabetical order).

**Access:** Physical barriers should not impede the access of users to telecare services, e.g. users with mobility impairments should not face difficulties to access and interact with telecare services.

**Accessibility:** Access refers to the ability of a client to avail him/herself of appropriate telecare services in a suitable manner. There are several aspects of accessibility, relevant to the present area:

- Telecare services must be accessible for all users, regardless of their abilities. A complementary "Design for All"/Assistive Technologies approach should guide designers during the entire telecare service provisioning process (conception, design, development, implementation, evaluation, deployment, sustaining and replacement), in order to ensure that accessibility aspects are properly addressed and covered.

- Accessibility of services requires that users have the necessary and adequate information concerning the services available (see also clause 7.3).

- Among the main purposes of delivering telecare services is to improve access to care by lowering geographical and other temporary barriers. The ongoing convergence in ICT, including such aspects as device miniaturization, low power consumption and more efficient battery technologies has led to the development of mobile services available through digital terminals using public mobile infrastructure. These terminals should provide ubiquitous and transparent access to telecare services, provided there exists an appropriate organization behind them.

**Information:** A telecare service must offer understandable information to users. Multimodal and redundant information should be offered, avoiding complex schemas for data representation and users should be able to ask for system messages repetition and for contextualized help (for a more detailed description clause 7.3). In addition, important information generated by the telecare service (e.g. notification alarms) must be made perceptible for users with auditory or visual impairments, or simply to users who are sleeping, or to users who are in a noisy environment or performing any task.

**Input:** Users, including people with mobility or speech impairments, should be able to generate input information, without difficulties. In addition, UI controls of telecare services should be easily reachable by all users, for example including wheel chair users, people with low motoric controls, and people who are significantly below the average height.

**Navigation:** Users need to easily understand how to navigate through the UI of a telecare service. People with cognitive or learning impairments may find it difficult to remember codes and step sequences, or to choose among a large set of options. They also may get confused with system malfunctions, when waiting a response from the system, or when the system is demanding an input. Such aspects should be taken into consideration and operational procedures should be kept simple. Multimodal, redundant interfaces should be supported.

**Output auditory:** Messages generated by the UI of a telecare device must be audible for system's users. Users with mild to moderate auditory impairments, people with acoustic technical aids and also people with cognitive impairments may experience difficulties to perceive auditory information and should be offered other options. Other aspects to consider include the sound frequency, message length and complexity. **Visual** messages generated by the UI of a telecare ser vice must be made visible and designers should take aspects such as size, contrast, colours, complexity and dynamical behaviour of graphics into consideration.

**Usability:** Design features of telecare services must optimize the quality of use, by means of proper adoption of user centered development methodologies (iterative processes which include engagement of users within the design of products and services). Telecare solutions should be optimized for aspects such as utility, effectiveness, accessibility, learnability, satisfaction of use, error robustness, reliability and stability.

**Usability testing:** Usability testing typically provides considerable quality improvements to the quality of a product or service and should therefore always be applied to telecare services. As there are no telecare-specific usability test methodology standards or recommendations available, [61] can be used for the ICT-related parts of telecare solutions.

## 7.2 Setup, configuration and initial use

The deployment of telecare services is often made more difficult than necessary, due to difficulties in installing and configuring services and devices and understanding the full potential of these services. These obstacles are even more emphasized by the:

- Changing population demographics: the number of older people and people with special needs is growing rapidly, requiring additional support and dedicated efforts for those unable to cope with ADL.

- Population mobility: as more people benefit from telecare services supporting mobile devices, it is required to optimize the user experience of these services with regard to the limited device capabilities.

- Increasing user expectations: users are getting used to plug-and-play systems with fully configured components. Similar, natural expectations are automatically projected to telecare services and should therefore be addressed.
- Telecare services deployed without a minimum level of satisfied pre-requisites (e.g. comfort of use, development of a trusted relations, basic skills and familiarity) will not be able to launch or become widespread.
- Increasing variability in the segmentation of customers, ranging from children to older people.
- User's inability and lack of interest to cover important (but in a normal, user-centred, functionality-oriented scenario, less relevant) aspects of their service and communication, such as security aspects.
- Human resource limitations: the complexity of telecare services exceeds the ability of many users, while personal assistance and support cannot be always offered.

As the hurdle to using remote telecare services is the highest for first-time users with limited pre-requisites, it is required that first-time access to these services is simplified as far as possible. This should preferably include pre-configured, ready-to-use service elements or as a minimum, provide clear guidance on how to configure and use the telecare service, as well as provide a description of functional capabilities.

Even with automated set-up procedures, user guides and quick reference guides will be necessary for day-to-day use, as fully self-explanatory user interfaces are far from becoming reality. Furthermore, human memory is far from perfect - users will always have a tendency to forget usage procedures or specific subsets of them (e.g. passwords or commands) over time.

Detailed guidance on the design, implementation and provision of set-up procedures for devices and services such that those can be set up and used by the largest possible range of users, with a continuity of access and use are provided in [86].

## 7.3 User education

Telecare users should be provided adequate information concerning the availability and functionality of the available service offering. Information can be provided through several channels, such as:

- national centres for the dissemination of social and telecare services and community equipment;
- healthcare centres;
- through the Internet; or
- using new approaches, like in the Italian city of Genoa, a one-stop-shop for information and advice about health and social services has been developed.

Furthermore, in order to be able to make proper use of deployed services, users should be able to understand , how to access and make use of the offered capabilities in a reliable way.

User education can play an important role not only in explaining how to use a telecare service, but also explaining how the service will benefit the user.

User guidance for telecare services are a necessity, as these services are:

- often complex;
- have inadequate input and output devices, due to various technical and cost-related limitations;
- provide an increasing number and range of functions, whilst the users are less specialized;
- sometimes presented in a seamless way, where certain functions are local and others provided by the telecare system- a distinction not always transparent to the user;
- sometimes difficult to understand and use.

A considerable number of problems with current user guidance are known and include:

- incomplete user guide;
- the information cannot be found;
- the language or structure of the user guide is inadequate;
- the explanation of how to use a telecare service is too abstract;
- the information cannot be perceived adequately;
- the telecare service functionality does not correspond to the available version of the user guide.

EG 202 417 [89] provides a clear set of guidelines on how user instructions ought to be provided, taking into account the requirement of different user groups (e.g. young, older people, disabled and less literate users) and the possibilities offered by different media. [89] stresses the importance of offering user instructions and other guidance that is appropriate for the user's level of expertise and cognitive abilities, the use of media (or a combination of media) that benefits the largest range of users, and structures that offer good navigation throughout user guides.

In addition, [89] provides generic guidelines that can help increase the uptake and usage of telecare services. An improved user education will help users to discover, understand and make use of the supported capabilities.

## 7.4 Ubiquity of access, interoperability, customization and personalization

Users' mobility requirements should be envisaged by service providers, as users may request services to be provided in their own homes, but also in other settings such as public schools, workplaces, recreation centres or even other countries (in which case, roaming between different telecare networks, with standardized services and levels of quality, may become necessary). Telecare functions may even become under-utilized if user's customization and personalization requirements are not met.

As such, requirements are becoming more and more common, service providers will need to operate across various vendors' systems and to comply with de-facto industry standards, protocols and even regulations. System specificity and sensitivity should be made available upon request and calibration tests should be designed and developed to ensure continued safe operation, as service provision moves from one supplier to another.

Telecare services need to, in many cases, be individualized, as users may require different configurations of functionality and support.

User profile information and supportive implementations may be used to provide users with the most suitable interaction modes to exchange information with the system, taking advantage of multi-modal and device-independent interaction approaches [7]. For example, telecare agencies can provide users with a personalized view of available services, according to user's requirements, needs, personal preferences including cultural preferences and the context of use (cultural issues are important to consider, as considerable parts of the population may find barriers to the understanding and use of telecare services, e.g. language).

## 7.5 Other human factors aspects

**Affordability:** this includes such aspects as the costs of installation, use and maintenance of the Telecare service. Even though this is a key enabling parameter for telecare systems, it should not be considered more relevant than other aspects, such as utility or dependability. Furthermore, it must be stressed that an integral assessment of benefits and costs of these systems should take into account the improvement of users' quality of life, required investment and resulting savings for social and health care departments, etc. The real provision of telecare services will probably require design and adoption of complex business models with multiple stakeholders, institutions, roles, and approaches, which are not always mature and well defined.

Because of the existence of different models of health and social care systems in Europe (some of them may even vary in the same country), it is foreseen that different financing approaches will be used. These will be typically organized from private or public insurance systems, or other welfare institutions. The user (or even her/his family) may be offered the services at no, partly or full rate.

Other considerations about the cost affordability of telecare services include the facts that:

- a considerable part of telecare services are based on ICT components and services, which are becoming more affordable to end users and organizations; and
- construction and building companies are slowly starting to provide structured wiring for home networks (this feature typically represent a small investment but is a necessary enabler).

The cost containment of telecare services can be influenced by the use of main-stream industry standards, technologies and components.

**Appropriateness:** The appropriateness of a technology used to provide telecare services refers to a judgment about whether the technology should be used in particular circumstances [48]. Appropriateness is a function of other attributes such as accessibility, safety, effectiveness and cost, in a particular situation.

Applications must meet regulations, practices, standards and user requirements. It is important to stress that technology is not used to compensate the human contact and interaction but to support it and save time from secondary, more routine activities. To guarantee the appropriateness, close collaboration between all stakeholders should be made possible.

**Availability:** Availability is defined by rights and opportunities to telecare services. It depends on the type of available social and health care services in a specific country and on the existence of the required technology and organizational infrastructure. The services can be public, private or a combination of them. In the European domain, there is a range of different health and social services [45].

**Effectiveness:** Effectiveness is the benefit of using a telecare service for a particular health problem in general or routine conditions of use, for example, in a community setting [48]. A main goal of telecare services is to satisfy user needs, with a special focus on allowing people to reach or maintain an independent living style. User requirements must be carefully defined, involving users in the design process and evaluating results to ensure product and/or service features will satisfy end users needs.

**Ethics and non-intrusiveness:** Even though there is common agreement about the potential benefits offered by telecare services to significant segments of the population, ethical issues need to be assessed. Part of those who will benefit from these services will depend on them in the same way they are now human-care dependant, and may have difficulties in raising claims about them. See clause 8.3.1 for more details.

**Safety and security of operation:** Certain actions involved in the operation and use of telecare services, performed by humans or the system itself, could imply safety risks for users of telecare services. Services should be developed within an error tolerance schema. Users of telecare services must be confident about the behaviour of the system and the functionality of the service, even in the worst or most critical conditions. This is also a key issue for people with impairments, who use such systems in order to perform their activities of daily living [49]. Vulnerable people should not be exposed to increased risks as a matter of ICT usage. Safety and security issues relating to the user experience of operation of telecare services should be studied in more detail and the implications for technical harmonization identified, so that appropriate recommendations and guidelines can be developed.

**Security and privacy of personal data:** Telecare service users have the right to control what personal information should stay private and what can be shared with the outside world. It is as well the right to control for which purpose personal information should be collected, maintained and used. Providers of telecare services need to make sure that the user right to privacy will not be lost and that technology advancement can be developed alongside privacy interests. See clause 8.3.2 for additional details.

# 8 Specific recommendations

## 8.1 Recommendations for telecare service provisioning elements

### 8.1.1 Electronic assistive technologies

Electronic Assistive technologies, EAT, are in many cases the enablers to the use of telecare services. This relation can be categorized in two main groups:

- EAT that help users in their interaction with ICT devices, which are part of the telecare equipment necessary to use the offered service; and
- integration, within the telecare infrastructure, of EAT that are not used specifically to help the interaction between the user and the telecare service, but which serve as aids for the activities of daily life (ADL).

Several recommendations are provided in clause 6.10 and not repeated here. The recommendations focusing on the standardization effort needed for the improvement of the user experience of EAT include:

- increase the adaptability, affordability and connectivity of assistive technologies;
- make the setup and operation of EAT simple and consistent;
- improve the interoperability among technical aids from different manufacturers or different functionalities, and also between technical aids and general purpose ICT equipment, and also with telecare and smart house infrastructures;
- integrate the support for EAT within the home telecare infrastructures and in existing and future main-stream technology standards.

### 8.1.2 Home safety and security monitoring

Advanced home environment safety and security monitoring will need standardization efforts in addressing and defining:

- what categories of safety and security devices need to be made available in the future to users;
- what categories of data and signals will be gathered;
- what kind of data will be gathered in every category;
- what aspects of security, privacy, ethics and non intrusiveness have to be considered, and how to address them;
- organizational requirements for care provision services related with home safety and security monitoring;
- technical aspects of integration of sensors within home systems;
- codes of practice to improve the professional management of social alarms services for improved planning, designing, performing and integrating telecare services;
- accessibility and usability of UIs to be offered to clients and carers, both locally and remotely; and
- dependability of systems that can be life-critical [24].

### 8.1.3 Information provisioning

Several recommendations are provided in clause 6.2 and not repeated here. In addition, the guidelines in [86] cover many other aspects and should therefore be used as a reference.

The following, more specific recommendations are provided for information provisioning services:

- customized, pushed information provisioning services should provide the necessary support and advice, customized to an individual's specific needs. These services should be directed in a context-dependent way but not self-navigated;
- customized, pulled information provisioning services should provide customized advice in direct response to questions and requests from clients and include access to self-help and discussion groups. The information should be professionally and selectively directed and proper menu choices for specific chronic diseases should be offered. These should be made available upon user request and not made location dependent (reachable at home and on the move);
- generic, pushed information provisioning services should provide general information and advice on an ad-hoc basis; and
- generic, pulled information services should make general information on health matters, lifestyle, illnesses, etc. available upon request.

It is recommended to take into consideration:

- what kind of information should be provided;
- who should provide the information;
- what channels should be used to provide it to the user;
- what channels should be a available to users to request information; and
- aspects about processing of home environment and personal data to automatically generate information.

Additional aspects of information provisioning will be addressed by future work.

### 8.1.4 Personal monitoring

Services related to monitoring of physiology and activities of daily living will need standardization efforts to focus on:

- defining what categories of safety and security devices and services should be made available to users;
- what categories of data and signals will be gathered; and what kind of data will be gathered in every category (this restriction is not required if [43] standards are employed - although there is opportunity for application profiles supported to be negotiated/declared at association);
- defining real time/non real time monitoring, more generally; (defined in [43], part 10201);
- defining invasive/non-invasive acquisition of data, more generally (should be aligned with [18]);
- what aspects of security, privacy, ethics and non intrusiveness have to be considered, and how to address them;
- organizational requirements for care provision services related to personal monitoring;
- technical and standardization aspects of integration of sensors within home systems (also addressed in [43]);
- accessibility and usability of UIs to be offered to clients and carers, both locally and remotely; and
- dependability of systems that can be life critical [24]- largely provided for in the IEC 60601 series of standards, in response to the MDD requirements [18].

### 8.1.5 Electronic health records

For a successful deployment of telecare services, a high level of data integration is needed between medical data from local patient data records, data from different sensors, and services provided by different companies. It is therefore probable that for large-scale deployment of telecare services to take place, a very active involvement by Governmental bodies, regulators and R&D institutions will be required.

The following recommendations are provided:

- already available standards for electronic health records should be applied;
- health-specific and social information should be integrated;
- health records should be made available and interoperable, on a local and European level when necessary, as requested in [29];
- user profile management [7] should be applied, where possible, to simplify the reuse of preferences, settings and options; and
- ethical, privacy and security recommendations presented in clause 8.3 should be applied.

### 8.1.6 Interoperability and integrability

As telecare solutions become widespread, care service providers will need to operate across various vendors systems, networks and possibly, countries. Such systems may also have been installed by the individual user or their family prior to the user becoming a formal care service client.

Additional service provision costs would be minimized if care providers were able to assess the functional ability of any pre-fitted telecare service and then adopt, or enhance and adopt, the existing hardware into their service package. For this to become a reality, the social and health care system suppliers must work together to support available, open standards and protocols. System specificity and sensitivity must be declared and calibration tests designed and made available to ensure continuous safe operation, as service provision moves from one supplier or network to another.

This technological openness will affect telecare services on two levels:

- Interoperability recommendation:
  - Home devices with heterogeneous nature and behaviour, possibly from different suppliers (e.g. biomedical sensors; flooding, gas and smoke sensors; computer equipment; home appliances, etc.) should be able to interact with one another through the home communication network.
- Integrability recommendation:
  - Telecare providers should offer products or services working well together in a solution-oriented integration. These applications and resources may be located within or outside the home environment; they may consist of home electronic equipment or may be provided through external, third party services.

## 8.2 Recommendations to stakeholders

### 8.2.1 Policy makers and regulators

The statements below, extracted from various EU policy framework documents, have been made by policy makers and regulators and illustrate the ambitions to deploy and use well-designed, reliable, safe, interoperable, pan-European, client-centric telecare services:

- "Empowerment of the European Union is linked to the sustainability of the well-being society, which highly depends on the development of Information and Communication Technologies" [42].
- "Projections suggest a decline in the supply of informal care provided to older people, resulting in increased admissions to residential care could have very considerable financial consequences. This highlights the importance of services to support informal carers and also requires substantial rises in formal services. Development of non-residential services, such as home care and day care, will be especially important" [88].
- "Telecare can help deliver policy objectives of enabling as many older and disabled people as possible to live independently and safely in their own homes and can contribute to a range of initiatives in health care, social care and housing, including: intermediate care, accident prevention, supporting people and valuing people" [68].

- "The key principles are that telecare should be: part of an integrated care package developed on the basis of a holistic assessment of individual need; and delivered as part of a comprehensive service with a technical and support infrastructure which meets high ethical and quality standards."
- "A comprehensive telecare service should include a robust infrastructure covering referral, assessment, specification of equipment, installation and familiarization, maintenance and review" [36].
- "The only barrier to making home and community-based services (HCBS) equal to institutions in any State in the country is political will" [70].

In order to contribute to the successful implementation of these deployment plans, the following recommendations are made:

- telecare services should be designed, developed, deployed and maintained in a user-centric approach, including carers and other users;
- available human factors, usability, technical and medical expertise should work together to define, develop and deploy telecare services in the most optimal way;
- a basic, common reference model on which to base an effective telecare service should be developed [69];
- clearly stated policies and actions to support independent living;
- basic key aspects (improvement of users' quality of life, required investment and resulting savings for social and health care departments) and roles (clients, care providers, managers, etc.) for elaborating integral business models should be studied and developed;
- the awareness of telecare services among the population, especially for clients and care professionals of care should be increased; and
- commonality of medical regulations in the EU/EFTA and with other countries, so that obtaining authorization for deployment in one EU/EFTA country makes it automatic, or at least easier to get authorization for deployment in other EU/EFTA countries (the CE mark for medical devices is for a large part fulfilling this need within the EU/EFTA but it is not recognized in the United States). Since the CE mark is based on self-declaration and obtained locally in one country, it is also important to avoid having countries "underselling" each other with respect to medical equipment requirements.

### 8.2.2 Standards developers

Standards can ensure that minimum levels of compliance and interoperability, necessary for the development, successful deployment and use of telecare services are met. In addition to the mostly non- end user centric recommendations provided in [60], the following recommendations should be regarded as guiding principles:

- available ETSI and other human factors and usability technical reports, guidelines, standards and norms (e.g. [1] to [2], [5] to [9], [12], [13], [25], [27] to [28] and [89]), covering ICT areas applicable to telecare services, should be taken into consideration during the specification, design, development, deployment, management and sustaining phases of telecare services;
- where the above is not applicable nor available, specific action should be undertaken to provide the necessary human factors and usability guidelines to designers, developers and deployers;
- a Design-for-All approach should always be taken: Telecare recommendations, guidelines and standards should always be based on client and carer requirements and developed in a user-centric approach. In addition to that, social aspects and implications of new services should be taken into account;
- minimum, generic usability and accessibility requirements should be defined and applied;
- safety and security of operation guidelines should be developed;
- security and privacy of personal data issues, as well as those related to ethics and non intrusiveness should be considered;
- standardized guidelines for the evaluation of human factors in telecare services should be produced;

- interoperability between telecare service elements and services should become an EU-wide priority, to ensure and support the delivery of interoperable, location-independent telecare services to citizens; and
- the relationships between telecare standardization and standardization of other areas (e.g. telemedicine, home systems, Next Generation Networks, ICT equipment and services, electro medicine equipment, etc.) should be studied and used to the benefits of telecare standardization.

### 8.2.3 Infrastructure providers

European communication infrastructure providers should, as an overall high-level goal, ensure that present and future European infrastructures meet the basic requirements on aspects of:

- interoperability of communication networks;
- integrability of telecare services;
- affordability of deployment to the general public;
- development and deployment of new technologies to support the specific, necessary enabling elements; and
- functional and electronically interconnectable buildings, also supporting the potential use of home networks.

### 8.2.4 Service providers

ICT and telecare service providers should work together to develop and ensure that the service elements, necessary for the successful use and deployment of telecare services, can be supported. The present document recommends:

- the use of user centred methodologies to design, implement and evaluate services;
- development of telecare services on the basis of a holistic assessment of individual user needs;
- active involvement of users, carers, voluntary organizations and suppliers;
- take into consideration ethical, privacy and security aspects applicable to telecare services;
- development of efficient service provider partnerships; and
- development and deployment of new technologies to support the specific, necessary telecare enabling elements.

### 8.2.5 Device, equipment and application developers

For devices and applications developed for and used by telecare services, it is recommended to:

- ensure a "Design for All" approach in all stages, considering user centred methodologies for designing, developing and evaluating devices;
- follow available human factors and usability recommendations, guidelines, standards and norms (ETSI and other), covering ICT areas applicable to telecare services, during the specification, design, development, deployment, management and sustaining phases of telecare services. Where applicable, this should include [1] to [2], [5] to [9], [12], [13], [25], [27] to [28] and [89];
- always perform usability testing, according to available recommendations and use the results to align products with user requirements and expectations;
- provide equipment compliant with main-stream technical requirements and standards; and
- support aspects of interoperability, integrability and openness and maintainability.

### 8.2.6 User experience and UI professionals

Recommendations provided to user experience and interaction design professionals include:

- ensure a "Design for All" approach in all stages, considering user centred methodologies for designing, developing and evaluating devices;
- follow available human factors and usability recommendations, guidelines, standards and norms (ETSI and other), covering ICT areas applicable to telecare services, during the specification, design, development, deployment, management and sustaining phases of telecare services. Where applicable, this should include [1] to [2], [5] to [9], [12], [13], [25], [27] to [28] and [89];
- usability testing should be part of all device, equipment, application and service development and deployment processes;
- areas where recommendations, guidelines or standards are unavailable should be highlighted to standardization bodies (e.g. ETSI) for future action.

## 8.3 Recommendations for ethical, privacy and security aspects of telecare services

### 8.3.1 Ethics and non-intrusiveness

"The use of information technologies in the home raises ethical questions concerning privacy, security, freedom of choice, dependency and consent. These are particularly important in the development of systems for people who are not able to control the technology themselves - for example, people with dementia or other mental impairments" [62].

Several strategies could improve the ethical and non intrusiveness aspects of telecare services. Based on [51], [53] and [54], the following recommendations are made:

- respect of the privacy of users;
- minimize intrusion when introducing telecare services and during the collection and use phases of client data (personal or gathered from monitoring systems);
- avoid the use of technical language, as this may interfere with the understanding of telecare services;
- take into account the role of relatives, friends and people providing informal care, and its implications in Telecare service provisioning;
- reduce the impact of the equipment in homes, by adapting the design, behaviour and other characteristics of relevance to the home environment;
- present telecare services and systems as tools of self-empowerment, rather than as an outward sign of dependency on external services and aids;
- telecare services should be promoted in ways that affirm positive views of the service users;
- regarding the independent living style for disabled people, feasibility of telecare services should always be offered as a complement or alternative to healthcare services delivered by human beings; and
- ethical codes of care professionals should be made applicable to all Telecare services.

### 8.3.2 Privacy and security of personal data

Privacy [73] is not just about hiding information or confidentiality but also about control, autonomy and integrity. It is the right of people to control what personal information should stay inside their own house and what can be distributed to the outside world. It is as well the right to control for which purpose personal information should be collected, maintained and used. Providers of telecare services need to make sure that the user right to privacy will not be lost and that technology advancement can be developed alongside privacy interests.

As a baseline, it could be expected that people's negative attitudes to privacy will reduce as the benefits and inevitability of living with pervasive sensing and computing technologies becomes more apparent. However, whilst the benefits of some aspects of telecare are compelling and immediate (e.g. the monitoring of cardiac arrest amongst high-risk patients), the benefits of "mass-market" (mostly preventive) telecare services are far less tangible or immediate. It is the growth of the latter applications that is in greatest danger of being severely restricted by privacy concerns.

Although telecare solutions in the EU will need to conform to relevant European and national regulations and laws (governing, for example, data protection), it seems unlikely that these alone will be sufficient to allay the privacy concerns of most users. For telecare solutions to become truly acceptable to a larger number of people, technology and service providers have to develop products that consider both security and privacy practices. The risks should be assessed and appropriate security measures and well-known practices should be defined to maintain the risks under an acceptable level. The aim is to increase the client involvement and allow the client to have more interaction with and control over the information about his status and behaviour with the final goal to improve the overall trust on the system.

Based on [74], [75], and the BT "Security and Privacy in Telecare" report made available for the purpose of the present work , the following recommendations are made:

- the client should be given clear notice of the presence of telecare technology in their environment. The notice should not only be in form of a contract, but the awareness of telecare technology should be made explicitly and redundantly;
- the client should be given the opportunity to engage and interact with their personal information and to understand the benefits of telecare technology;
- there should not be any prohibition on clients to control their personal information. The client should be offered the control on which information is revealed from his home environment. Policies should allow the user to temporarily or definitely disable a sensor, or even the entire system (in combination with proper warnings related to the potential risks involved);
- the telecare system should provide to the client a clear and complete access to the personal information collected. Methods and rules applied to personal information should be accessible to the user;
- telecare technology should not be deployed to monitor and identify people that are not directly associated with a telecare service. Furthermore, personal identifiable information should be kept secure and separated from the information collected from the system;
- telecare service must not be exploited in any case for marketing purposes, or to collect or derive personal information about consumer product habits;
- information must be collect in a secure way. Transmissions between data collectors and data storage systems must be secure and must prevent eavesdropping and "leakage" of data. Databases and data transmissions should only be accessible to authorized users or other stakeholders; and
- measures should be put in place to ensure compliance to the regulations. The client should be able to complain where its privacy has been violated.

Two distinct challenges are identified in terms of privacy and security:

- It is necessary to ensure that a client is monitored with the correct security requirements, and also that the data collected cannot be eavesdropped or accessed without authorization.
    - Requirements should be considered in terms of privacy for access control and in terms of security for confidentiality, authentication, management of access control and auditing.
- Personal information must be securely shared among multiple carers, public health services and private enterprises. Privacy concerns about information flows across multiple domain of ownership or control can stop stakeholders in participating in data sharing. Users will be concerned about the likelihood of that party keeping the information very secure, and to only use the information for its intended purpose.
    - Users should have the possibility to control information about them and decide how the information should be used and how much information should be divulged.

- Service providers should be made accountable for the usage of these data and they should be liable for the violation of personal privacy that may result.

There are three non-exclusive strategies to follow to address telecare service user's privacy concerns:

- Keep the information as local as possible: This strategy is a design principle to allow the flow of information only when there is a real need. By restricting the flow of raw data information, we restrict the number of parties who hold personal information, and its potential for malicious use. Recommendations in this direction include:
  - process all the sensor information locally, within the domain of the user, and make it available to third parties in emergency situations, or when necessary;
  - send aggregated information specifically suited for the needs of a particular recipient and application;
  - send anonymized information when the patient identity is not required for diagnosis or monitoring.
- Give control to the user: users' privacy concerns are alleviated by providing them with the power to control their own information, irrespective of whether they actually use this power. This is an important psychological aspect of people's attitude towards privacy that we should acknowledge rather than ignore. Provide users with:
  - a mechanism to set up and configure (possibly with expert guidance) the telecare service in such a way that it shares the information they want to share with those with whom they want to share it;
  - the possibility and necessary controls to switch off or deactivate the sensing system when they particularly wish to have stronger privacy for a period of time; and
  - a function allowing to retrospectively delete a (shorter) period of time from the local system's records (e.g. if the data were only analysed once per month, the user might value the ability to "delete" of particular days activity if they feel it excessively intrusive).
- Promote industry privacy standards: The potential burden of individually configuring users' information sharing policies may be alleviated by the development of widely agreed industry standards (effectively, establishing new social norms). In the same way that users are persuaded by the banks to accept chip & PIN technology, the definition and widespread publication of privacy standards within telecare may reduce individual users concerns. It is recommended to:
  - allow the user to select standard templates of information sharing, enabling different telecare services;
  - support regulations and industry and de-facto standards, e.g. [13], [18] and [95];
  - standardization can also support users between different service providers to share their privacy concerns and help each other establish their privacy requirements. It also allows the migration of users between services without the massive burden of understanding a new service and the privacy concerns and controls.

In addition, it is recommended to consider:

- defining the information required, not only to the understanding and control of personal information, but also to the operators who must fulfil such roles in collaboration with different entities. As a simple example, it would probably be beneficial to standardize the information sent to various emergency services in the event that the system detects an emergency.
  - Standardizing the conditions under which private information flows across the different domains, for example, recommending lifestyle data to be maintained locally and only made accessible to specified healthcare professionals 30 days after its acquisition.

Central to several of the above recommendations are the high-level issues of:

- enabling users to have simple and comprehensive control over the privacy of their personal information;
- ensuring that their personal information is only shared with the correct people or organizations.

The use of user profiles and good practice in the management of those profiles will be essential to successfully address the above issues. Comprehensive guidance on user profile management can be found in [7]. Being able to locate and identify the correct person or organization to which personal information should be sent to and identify the person or organization requesting access to the client's personal information is essential to ensure that the client's privacy requirements are met. Identification solutions that are effective in a wide range of communication scenarios will be required to achieve this. One example of such an identification solution is the Universal Communications Identifier, UCI [110].

# 9 Conclusions, general recommendations and future work

This clause provides our final conclusions and recommendations, made on the basis of the present document and results of the technical studies, consultations and liaisons within the previous tasks. These will be used as the basis for recommendations to ETSI and other stakeholders for actions and further work in this area.

In the present document, telecare is defined such that it relates to client-oriented services delivered principally into the home. It is shown that the end users of telecare services include carers and coordinators in addition to the client. Telecare has national and European support at governmental level because it has the potential to deliver services to more clients and more efficiently than existing face to face based services. Only by embracing such efficient methodologies can governments hope to deliver all the services that will be required by the aging population of Europe within acceptable costs.

Telecare is generally associated with care of older people, however, it has been shown that telecare is applicable to the whole human age range from babies, through childhood, adults and older people. Additionally, many users in need of telecare may have physical, cognitive or other impairment, which may be temporary or permanent. Telecare solutions must embrace the philosophy of design-for-all, promoting accessibility by as large a majority of end users as possible. Complementary solutions based on assistive technology must be available when required.

There are opportunities to create additional benefits for clients, by integrating home safety monitoring and control systems with both health and social care oriented telecare systems. For maximum usability of telecare systems by the general population, more effort should be put into the design of hardware and user interfaces, with close attention paid to the opportunities of creating a single user interface, applying generic UI elements to control multiple applications and services for the client, carer or coordinator. Systems must be designed to be fail-safe, not promote excessive dependency and be controllable and maintaineable remotely by carers or coordinators, when appropriate. To promote service oriented competition and innovation, client side hardware and software should ideally be interoperable with multiple service providers. Standards for data exchange between devices, and definitions and support of ontologies between services must be further developed to support this vision. Security and privacy issues will be key to the success of future telecare services. Further robust ethical guidelines must be debated and developed in order to best preserve the appropriate control, privacy and dignity of all users, under all circumstances.

Furthermore, guidelines for usability testing of telecare service elements and system and service evaluation methods should be developed, based on commonly available and well established methodologies and procedures, adapted to the specifics of telecare users, products and services.

A specific aspect of telecare is the remote monitoring of physiological parameters, particularly for those with chronic disease. This aspect of telecare has begun to move from trial to service delivery in the last 3 to 5 years in USA, Europe and Asia as business models, and user acceptance have been proven. This application is likely to advance rapidly in response to governmental desire to improve the treatment and outcomes of those people with long term conditions.

The social monitoring, electronic assistive technology and information provision aspects of telecare are shown to be related to the many existing initiatives on "Smart Housing". These may all derive benefits in equipment usability and affordability as the Smart House market evolves.

Whilst there are differences in health and social care provision and financing between countries of the EU, in all cases there are multiple stakeholders concerned with the provision of potential telecare services. The design of new care services, care pathways and financial models will be required to ensure that telecare becomes embedded in day to day service provision. Incorporation of telecare systems, or enabling technology, should be considered in the design, build and refurbishment of all properties that may be occupied by a recipient of telecare services. Appropriate incentive schemes or regulatory frameworks should be considered in detail to ensure that widespread service deployment is not inhibited by market, inter-governmental or inter-departmental lack of coordinated goals.

Interoperability between telecare service elements with focus on the optimization of the usability of telecare services is of paramount importance. As it is foreseen that telecare services will be made available across national borders within the EU and EFTA, the interoperability of telecare services should become an EU-wide priority. We recommend to initiate and perform such PlugTest events, focusing on user aspects, e.g. the interoperability of human factors aspects of telecare services.

The current level of standardization for the provisioning of telecare services is neither adequate for easily connecting different types of equipment together, nor for integrating equipment from different suppliers into a common communications infrastructure. Standards for connectivity should be agreed and applied.

Furthermore, as physical connectivity by itself is not enough, a common terminology and nomenclature (irrespective of differences in sex, age, organization, professional level and nationality between health workers) should be developed and deployed.

Detailed consideration should be given to new methodologies to support the widespread communication of telecare system capabilities and benefits. Whilst governmental efforts to promote the uptake of telecare have begun in some member states, so far this has been aimed at service providers and industry stakeholders. Serious consideration must be given to communication to all potential end users. Market growth in telecare will be accelerated if potential end users make informed demands on their health and social care providers. This will not happen unless effective, simple to understand telecare communications plans for the general public are developed and executed.

Ethical, privacy and security aspects of telecare services, such as the privacy of personal data or ethical and non-intrusiveness issues should be made understandable and manageable to clients and other users. It is recommended to consider the development of understandable, non-technical, user-oriented formats for the areas of privacy and security.

With respect to future directions in the telecare human factors area, a proposal for future work has been submitted to create an ETSI Guide addressing the action lines in the European Commission's *e*-Europe 2005 mid-term review. The proposal requests the development of "User experience guidelines for telecare solutions (*e*-Health)", based on the preliminary results provided by the present document. The proposed ETSI Guide should continue the important human factors work in telecare, by developing detailed user experience and user interface guidelines.

# History

| Document history | | |
|---|---|---|
| V1.1.1 | August 2005 | Publication |
| | | |
| | | |
| | | |
| | | |